CONFRONTING "THE STARE": WOMEN WITH DIS/ABILITIES,

NEGATIVE CULTURAL REPRESENTATIONS, AND RESISTANCE

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by

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Abstract

CONFRONTING "THE STARE": WOMEN WITH DIS/ABILITIES,

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Janet Ellen Schaller

Persons whose bodily configuration is judged as different by cultural norms

encounter devaluation of their bodily variance in the eyes and faces of others. Often this

is revealed through "the stare," a symbolic gesture with multi-faceted meaning that

focuses on a single bodily characteristic, conveys power dynamics, indicates attitudinal

barriers, and categorizes people.

This dissertation is a qualitative study based largely on interviews with five

women with visible physical dis/abilities who shared experiences of being objects of

stares. As a work in pastoral theology, care, and counseling, the human being in her

context is regarded as primary text. Other resources include dis/ability studies literature,

theological writings, and psychoanalytic theories.

The stare as oppressive gaze assesses women with dis/abilities and recreates the

image of dis/ability that society has already constructed. The narratives of women with

dis/abilities challenge these narrow stereotypes. In conjuring up negative representations

of women with dis/abilities, the stare threatens annihilation through literal physical death,

as people of value, and as women. The stare is a type of failed mirroring, because it

reflects an inaccurate picture of the individual and mirrors cultural assumptions instead.

Stories of confronting the stare reveal internal dynamics, including clashing realities,

internalized ableism, and inner protest. Interpersonal responses to the stare include

seeking sanctuary, turning the tables, telling the story, speaking up, expecting respect, educating, and turning off the power of the stare and turning on the power of life.

Affirming and mutual relationships and confidence in God's acceptance and care prevent major harm from occurring following an encounter with the devaluing stare and help heal previous damage. Christian traditions contribute to the problem of devaluation and also contain resources for liberation. Christians can rethink embodiment in a way that celebrates the goodness of all creation and calls forth alternative narratives to challenge narrow concepts of what is acceptable and good in bodies. Ministries of care join women with dis/abilities in separating cultural representations from their own self-knowing, by nurturing the urge to resist diminishment, in recognizing and reevaluating their own biases, and by assisting communities of faith to become places where every body belongs.

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CHAPTER 1

INVESTIGATING THE SOCIAL MEANING OF A LOOK

In Medieval Europe, people feared the stare of the basilisk, an evil and dangerous

creature—half cock and half serpent—whose glance was reputed to be deadly. As the

basilisk was presumed to dwell primarily in the desert of Northern Africa, prudent

individuals traveling across the desert protected themselves in order to ward off the

basilisk's stare. The preferred strategy was carrying a true cock, whose crowing would

stop anything evil in its tracks. The traveler could also take along a weasel, the only

animal not affected by and able to destroy the deadly basilisk. As the basilisk was not

immune to the sight of itself, covering oneself in mirrors was another protective device.[1]

We who are enculturated in scientific methods see ourselves as too sophisticated to

believe such cross-breed animals exist, much less that the glance of one could strike a

person dead. The basilisk and its dreaded stare are relegated to legend. Nonetheless,

popular sayings such as "if looks could kill" reveal our recognition that some looks are

anything but innocent. The ordinary activities of seeing and being seen convey important

messages.

> [A]n exchange of looks between animals is the usual prelude to all manner of
> social interactions, from casual acquaintance to fighting and sexual intercourse;
> animals are as well aware as we are of the difference between an indifferent look
> and the basilisk glance that is all power and intention.
>   Such a glance has all the makings of a symbol, in which an instinctual
> reaction is put into the service of social meaning. . . .[2]

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[1] See glossary entry, "Basilisk," in John Cherry, ed., *Mythical Beasts* (San Francisco: Pomegranate Artbooks in association with British Museum Press, 1995), 169; Francis Huxley, *The Eye* (London: Thames and Hudson, 1990), 4; Peter Lum, *Fabulous Beasts* (London: Thames and Hudson, [1952?]), 37-45; Alison Lurie, *Fabulous Beasts* (New York: Farrar, Straus and Giroux, 1981). I thank Janet Muff for calling my attention to these sources and the basilisk.

[2] Huxley, 4.

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In this work, I focus on a certain look—the stare—a kind of basilisk glance symbolizing powerful societal meanings and intentions communicated through the dynamics of interpersonal relationships. The stare is a basilisk glance directed at people perceived by dominant cultures as different. It is a look with "power and intention. . . . a symbol . . . put into the service of social meaning."[3]

Problem

This dissertation investigates problems associated with the stare—the definition and devaluation of persons as Other, threats posed by false cultural assumptions, negative attitudes communicated through interpersonal interactions, power dynamics inherent in such a look, religious and other cultural biases that support the stare, and internal and interpersonal challenges of being the object of stares.

I explore the experience of the stare primarily from the perspective of the person stared at, perceived as different, as Other. Women with visible physical dis/abilities constitute a group of people who experience the stare and are perceived as Other on at least two counts—gender and ability. Some of the women whose perspective I seek are Other in additional categories, such as race and sexual orientation.

At least in the United States, the cultural devaluation faced by women with visible physical dis/abilities relies upon the cultural valuation of the visual, wherein seeing or observing is a crucial component of knowledge. English speakers often equate seeing and knowing: "Seeing is believing." ; "I'll believe it when I see it." Being the object of

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[3] Huxley, 4.

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stares, usually from nondisabled people, tells women with visible physical dis/abilities that they are seen and known as Other and judged negatively.[4]

The stare generally is unidirectional. Persons most like what a dominant culture considers valuable stare at people to whom they and the culture attribute difference. Thus, culturally-determined power dynamics and judgments in interpersonal relationships are revealed. The difference is outside societal norms—it is viewed as abnormal, wrong, defective. The stare communicates a society's dissatisfaction and discomfort with difference and those who bear it. It re-creates and concretizes attitudinal barriers. Like the basilisk glance, the stare is a powerful reminder of the meaning a society makes of difference and the culture's intention to exclude, even annihilate, the object of the stare. In *Extraordinary Bodies*, literary critic and dis/ability studies scholar Rosemarie Garland Thomson explores a cultural construction of bodies and identities as this pertains to women with dis/abilities. She states that "the stare is the gesture that creates disability as an oppressive social relationship. And as every person with a visible disability knows intimately, managing, deflecting, resisting, or renouncing that stare is part of the daily business of life."[5] Like medieval travelers across the desert, those at whom the stare is directed form strategies to prevent it from being deadly.

For women with physical differences, the issue is complicated by the societal overvaluing of attractiveness in women (especially, as compared with men). Both the

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[4] It may seem as if this focus on the visually apprehended stare has no relevance to women who cannot see. However, the same negative judgments are perceived. Deborah Kent, a woman who is blind, says, 'I can't remember a time when I wasn't aware that I was different from most people, and that my differentness was a judgment against me." Deborah Kent, "In Search of a Heroine," in *Women with Disabilities*, ed. Michelle Fine and Adrienne Asch (Philadelphia: Temple University Press, 1988), 90.

[5] Rosemarie Garland Thomson, *Extraordinary Bodies* (New York: Columbia University Press, 1997), 26.

cultural expectation of bodily attractiveness in women and the societal devaluing of bodily differences in all people suggest that women with dis/abilities do not measure up to society's definition of fully woman or fully human.

Theology and religion have been misused to support devaluation. Christian religious traditions, texts, and practices contribute to social attitudes and practices. Institutionalized within the church are the same negative valuations of persons with dis/abilities as found in secular culture. The Levitical codes exclude persons with "blemishes" from attending to God in the most sacred of worship chambers. The healing texts in the gospels are often interpreted to mean that Jesus bestows "wholeness" when he cures persons of illnesses and dis/abilities, implying that wholeness and dis/ability cannot exist in the same person at the same time. Images of physical impairment (blind, lame, deaf) used as metaphors for spiritual deficits are common. Many church buildings are inaccessible to persons with dis/abilities. Nondisabled church members may feel awkward and uncomfortable interacting with persons with dis/abilities and, therefore, are less welcoming and more distant. Chancel steps continue to bar many persons with physical dis/abilities from worship leadership. Pastoral practice may focus on dis/ability as a tragedy rather than one of the many vicissitudes of life, on persons with dis/abilities as needing assistance rather than capable of making contributions to the life and work of the congregation.

Persons with dis/abilities and nondisabled persons are also exposed to, and accept for our own, values that are contrary to such negative messages. Families or subcultures may teach alternative ways of perceiving, doing, and being. We listen to ourselves—body, mind, and soul—and learn to see ourselves and the world through an

inner knowing. Women with visible dis/abilities do not accept wholesale everything their cultures say. When negative cultural messages conflict with our perceptions of ourselves, we sometimes resist the assumptions, conclusions, and acts of discrimination. Theological and spiritual beliefs support resistance to oppressive messages and relationships.

Cultural devaluation and stereotyping of women with visible dis/abilities, resistance to societal ideology, and the internal and interpersonal dynamics that result are all raw materials for pastoral theology and the practice of ministry. Religion and other aspects of culture mutually influence one another. The Christian church, for example, has made significant marks on many cultures—Christian views of the body are a pertinent illustration of these marks. For persons participating in Christian churches in North America, culturally formulated ways of looking at people and the world are impossible to escape. Therefore, the study in this dissertation of the ways social and religious messages inform nondisabled people and women with dis/abilities about themselves and each other offers persons involved in ministries of care insight into dynamics between women with dis/abilities and others, as well as into the struggles and strengths of women with dis/abilities. This exploration of the staring relationship and its effects contribute to the ability to assess such an interaction in a new way, resist its negative effects, and design communities of faith in which people with dis/abilities and nondisabled people participate according to their abilities, not social stereotypes or conventions. This study enables more appropriate care for nondisabled persons unfamiliar and uncomfortable with women with dis/abilities, and for women with dis/abilities when they are in a position of receiving care. This study of the stare

encourages other theological and psychological reflections on the part of people in

pastoral positions regarding assumptions about dis/ability and women, physical bodies,

and relationships within communities of faith.

Thesis

The narratives of women with noticeable dis/abilities reveal a disparity between

dominant society's assumptions about dis/ability in the United States and the actual

experience of living with a dis/ability. Though an act of staring may express a variety of

motivations and intentions, the stare as identified in dis/ability literature is a gesture with

symbolic meaning that focuses on a particular feature of a person's body,[6] makes a

statement of valuation, feels deadly,[7] divides people into categories, and creates a social

barrier.[8] The stare, as a cultural practice toward people with dis/abilities, conjures up

negative cultural images of dis/ability, leads to the enactment of exclusionary and

annihilating tactics toward women whose corporeal existence includes dis/ability, and

communicates cultural assumptions to those who are the objects of it. The stare is an

experience of failed mirroring. Women with dis/abilities who come face to face with

"the stare" and its accompanying messages are confronted with the complex task of

processing internal reactions, responding to the interpersonal exchange, and resisting the

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[6] One minister born with "congenital limb deficiencies" states that "[i]t is almost impossible for me to be inconspicuous. When I go to the zoo, I am quite able to compete with the animals for attention." Geyla Frank, "Beyond Stigma: Visibility and Self-Empowerment of Persons with Congenital Limb Deficiencies," *Journal of Social Issues* 44, no. 1 (1988): 101 and 111.

[7] Anna, a high school student, describes the stare as "kind of like a vampire bite—it sucks life out of you." Ann Cupolo Carrillo, Katherine Corbett and Victoria Lewis, *No More Stares* (Berkeley: Disability Rights Education and Defense Fund, 1982), 50.

[8] "In battling [the stare barrier] to gain compassion and human rights we confront more elusive enemies [than with architectural barriers]: hidden fears and habits of 'keeping one's distance.' Persons with disabilities meet people who refuse to look their way at all, a degrading and humiliating experience. Or, they meet indifferent people or those bent on satisfying their own curiosity, an irritating experience." Stewart D. Govig, *Strong at the Broken Places: Persons with Disabilities and the Church* (Louisville: Westminster/John Knox Press, 1989), 12.

judgment contained within the stare. The interplay between the stories of women with noticeable dis/abilities and pastoral theological reflections provide insights that challenge false assumptions and discriminatory practices and lead to the possibility of effective care for women with dis/abilities, those who are uncomfortable with them, and the communities of faith that incorporate both.

Methodology

The method I use in this dissertation for doing pastoral theology is multi-faceted. It begins with lived experience, engages society and religion, aims for effective care, gives priority to the experiences and thoughts of women, and seeks transformative paths. These categories are neither discrete nor sequential. Each is in dialog with the others and may expand upon another.

At the heart of my method is lived experience, that is, the experience of "living human documents." Anton Boisen, a leading figure in early twentieth century pastoral care, used the term "the living human document" when emphasizing the importance of learning from particular human beings in their specific context.[9] In this dissertation, the "living human documents" on whom I focus are women with dis/abilities. I am especially interested in the experience of being the object of the stare and the process of resisting negative cultural messages that may be inherent in the stare. The larger context is contemporary, English-speaking, North American society, a culture that often presents inaccurate, incomplete, and devaluing cultural representations of women with dis/abilities. Intertwined within this society are Christian faith, texts, theologies,

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[9] Charles V. Gerkin, *The Living Human Document: Re-visioning Pastoral Counseling in a Hermeneutical Mode* (Nashville: Abingdon Press, 1984), 200 (Chap. 2, n. 1) recalls Boisen using the term in a 1950 address, which was later published in the *Journal of Pastoral Care* 9, no.1.

practices, and traditions. An analysis of the helpful and/or harmful societal and faith-based constructs and practices reforms theological and societal concepts and identifies practices of care that promote the well-being of women with dis/abilities and the communities to which they belong.

My pastoral theological framework takes a feminist approach—it gives priority to the experiences of women. In privileging the knowledges of women with dis/abilities, I accept as normative a group of people at least doubly marginalized in contemporary culture, including many communities of faith. People with dis/abilities have been and often are treated and viewed as alien, while nondisabled people are considered the "norm." Attention is focused on disabled bodies, but the persons with those bodies often go unacknowledged. Similarly, dominant culture in North America has regarded women as Other and men as the "norm." Historically, men in power have largely ignored what women thought, did, or said but paid attention to women's appearance. They stared at and admired some women's bodies. Pin-up "girls" and centerfolds in men's locker rooms are legend.

Putting women with dis/abilities at the center of this dissertation both challenges early feminist agendas and extends them. Nondisabled feminists and women with dis/abilities have had a strained relationship. Through the second wave of feminism in the last century, women began to make their needs and demands known. However, the concerns of women with dis/abilities were not very visible in early feminist visions. This is changing. Feminists are realizing that studying difference enriches the field of women's studies. In the past decade or so, more women with dis/abilities who are scholars and/or activists have been researching, speaking, and writing on issues related to

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women and dis/ability. I attended a conference several years ago on the topic of gender and dis/ability where I met a few nondisabled women studying and writing about issues of concern to women with dis/abilities. Furthermore, the conference was sponsored by a group whose purpose is to research issues of interest for women in general. However, a feminist pastoral theological focus that privileges the experiences of women with dis/abilities is still rare.[10]

Putting women's stories at the center also contributes an element of focus to this work. The common cultural representations of women with dis/abilities are different than typical images of men with dis/abilities. A study of literary characters with dis/abilities reveals that authors use men with dis/abilities to symbolize the demonic.[11] This is not the case for women with dis/abilities, who tend to be portrayed as passive, helpless, and inferior.[12]

My pastoral theological method is supported by narrative theories and methods. This is a qualitative study. In order to discover the experiences and knowledges of women with noticeable physical dis/abilities, I conducted five interviews. Each interview was one to two hours long. The interviews were taped, one by audio-recording and the other four by videotaping. I later listened to or viewed the tapes several times, transcribing the portions used in the dissertation. Some of the interviews were arranged by friends or acquaintances who knew persons who were interested in telling their stories.

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[10] One example of work that look at women and dis/ability from a pastoral care perspective is Paula Buford, "Women with Acquired Disabilities," in *In Her Own Time*, ed. Jeanne Stevenson-Moessner (Minneapolis: Fortress Press, 2000).

[11] Leonard Kriegel, "The Cripple in Literature," in *Images of the Disabled, Disabling Images*, ed. Alan Gartner and Tom Joe (New York: Praeger, 1987), 31-35.

[12] Deborah Kent, "Disabled Women: Portraits in Fiction and Drama," in *Images of the Disabled, Disabling Images*, ed. Alan Gartner and Tom Joe (New York: Praeger, 1987), 47-63.

Some women volunteered for this project after I announced my research on an internet listserv that focuses on issues of relevance to women with dis/abilities. Others I personally contacted due to previous conversations that indicated an interest in this work.

I went to the interviews with a long list of questions I might ask and a short list of topics I hoped to cover. However, the questions or topics got in the way of my primary goal of listening to their stories.[13] Therefore, I decided in the midst of my first interview to keep the lists available but to refer to them only in case of a lull in the conversation. I rarely consulted the lists during an interview. Each woman had stories to tell or comments to make, and one experience led to another. One question I asked specifically was about experiences of the stare. Interestingly, the responses often took the direction of narratives of devaluing confrontations in general. While viewing or listening to the tapes, I looked for narratives of encounters with the stare, narratives that illustrated life as a woman with a visible dis/ability, women's encounters with cultural or religious representations or assumptions, important values or beliefs, contact with communities of faith or faith perspectives, women's own interpretations of life events, and acts of self-affirmation. My analysis of the interviews focused on internal and interpersonal dynamics, methods of resisting dehumanization, effective or ineffective care, and a comparison of lived experiences as a woman with a dis/ability with cultural narratives about dis/ability.

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[13] A similar problem is also noted by Lyn Mikel Brown and Carol Gilligan, *Meeting at the Crossroads* (Cambridge: Harvard University Press, 1992), 19. "[W]e decided to let go of the self-imposed pressure to cover every question on the interview protocol. Instead, we would use questions as openings. . . . We would follow the associative logic of girls' psyches, we would move where the girls led."

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My methodology was inspired by African theologian Mercy Amba Oduyoye's *Daughters of Anowa: African Women and Patriarchy.*[14] Though not intended as a work in pastoral theology, her methods and goals have much in common with the concerns of pastoral theologians. In *Daughters of Anowa,* Oduyoye analyzes culturally-determined and culturally-sanctioned norms for gender (especially women's) roles and behavior, the social transmission of these roles, and the outcome of the expectations for and treatment of African women. Furthermore, Oduyoye critiques these norms, expectations, values, and cultural practices in light of God's call to full humanity for all persons. She presents a vision of more just and life-giving relations between women and men in Africa, a vision of Christ's promise of liberation as it might be if enacted in African culture. Her study of women in an African context serves loosely as a model for my work.

There are significant differences between her work and mine. Content is a particularly obvious one. The group of women, their context, the areas on which I focus, the choice of cultural representations, and societal assumptions are all very different from hers. In addition, my dissertation is situated within the discipline of pastoral theology, while Oduyoye writes from a liberation theology perspective. Much of my analysis revolves around specific narratives of particular women who live with dis/abilities, and Oduyoye is focused on African women in general.

Yet, it is Oduyoye's vision of tranformative possibilities that exist—often unrecognized and unacknowledged—within Christian faith and other aspects of culture that especially excites me. Describing liberation as she introduces her paraphrase of Jesus' reading of Isaiah as reported in Luke 4, she proclaims, "All limitations to the

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[14] Mercy Amba Oduyoye, *Daughters of Anowa* (Maryknoll, NY: Orbis Books, 1995).

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fullness of life envisaged in the Christ Event ought to be completely uprooted. Jesus

came that we might have life and have it more abundantly."[15] In the Christian

understanding of the Divine work in Christ, the fullness of life is promised to all

humanity. It depends upon neither geographical location, ability, gender, race, sexual

orientation nor any other human characteristic that one could name.

Resources

This dissertation draws upon four types of resources—first-hand accounts of

women who live with dis/abilities; dis/ability studies literature, with particular attention

to resources that focus on or are written by women with dis/abilities; theological

literature related to embodiment or dis/ability; and object relations theories about the

concept of mirroring.

The first-hand accounts of women experiencing life through nonconventional

bodies[16] come primarily from the five personal interviews I conducted.[17]

> Joanne is an African American woman in her fifties. She is a poet and an active
> member of her community of faith. She states that she "was born with cerebral
> palsy," which she describes as affecting her body movements and her speech.

> Camille is an European American woman in her forties. She is an artist who
> creates in fabric and is a member of a community of faith. She acquired a
> dis/ability in her early twenties. She refers to her dis/ability as "dystonia" and
> describes it as pertaining to neck spasms that lead to involuntary and
> uncontrollable head movements.

> Rebecca is an European American woman in her twenties. She is a scholar in
> literature and dis/ability studies. Though a member of a community of faith as a
> child and youth, she has become dissatisfied with the church's theology and no
> longer considers herself a Christian. She describes herself as having a

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[15] Oduyoye, 4.

[16] Nonconventional bodies is a term used by Nancy Eiesland, *The Disabled God* (Nashville: Abingdon Press, 1994).

[17] Pseudonyms are used unless prior written permission was granted to use given names. Non-essential data has been changed for the purpose of confidentiality.

"reverential view towards nature." She became disabled after surviving traumatic injury from an automobile accident.

Liz is an European American woman in her fifties. She is a dis/ability rights advocate. Her dis/ability is related to a spinal tumor discovered in early childhood. A mainline Protestant denomination was part of her upbringing, though she no longer attends church. She expressed an interest in spirituality and metaphysics.

Edie is an European American woman in her twenties. She was between school and work when I interviewed her. Her dis/ability from a spinal cord injury was caused by a diving accident. She was reared in a mainline Protestant denomination but recently claimed Buddhism as more compatible with her personal beliefs.

At the time of the interviews, the women ranged in age from late twenties to mid-fifties and lived in different parts of the country. Four had attended college—one earned an associate's degree, three had some graduate work; one did advanced training in her profession after high school. One woman described herself as a lesbian, three indicated past relationships with men, and one said she was not at all interested in an intimate relationship. One had a partner, the others did not. Four are European Americans, and one is an African American.

A second group of resources comes from dis/ability studies literature, which has increased dramatically over the past two decades. Much of the literature is written by people with dis/abilities. Some of it records personal accounts of the experience of living with a dis/ability or chronic illness. Anthologies, such as *With Wings* and *With the Power of Each Breath*, tell of the lived experience of women with dis/abilities.[18] Works by Nancy Mairs, Audre Lorde's *The Cancer Journals*, and *Exile and Pride* by Eli Clare are resources for learning of the authors' experience with multiple sclerosis, breast cancer,

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[18] Marsha Saxton and Florence Howe, eds., *With Wings* (New York: Feminist Press at the City University of New York, 1987); Susan E. Browne, Debra Connors, and Nancy Stern, eds. *With the Power of Each Breath* (Pittsburgh: Cleis Press, 1985).

and cerebral palsy, respectively.[19] Women with dis/abilities, such as Susan Wendell, Jenny Morris, and Rosemarie Garland Thomson, are doing scholarly work in the field of dis/abilities studies.[20] Those writings, plus the edited volume *Women with Disabilities*, assist me in laying out the problem of cultural representations of dis/ability and the challenges such images present to women with dis/abilities.[21]

Writings on dis/ability and embodiment from scholars of religion and theology form a third group of resources I consulted. Nancy Eiesland, in *The Disabled God: Toward a Liberatory Theology of Disability*, centers her work on the need for new symbols in the Christian church, especially symbols that are empowering to and inclusive of persons with nonconventional bodies. Eiesland teams up with Don Saliers to edit a volume that focuses mainly on worship and dis/ability in *Human Disability and the Service of God*.[22] Kathy Black offers *A Healing Homiletic* for persons preaching on the healing texts in the New Testament.[23] Her first two chapters provide a concise summary of some of the ways the Christian tradition has contributed to prejudice and misconceptions about dis/ability. David A. Pailin explores issues of dis/ability and theodicy in *A Gentle Touch*.[24]

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[19] Nancy Mairs, *Carnal Acts* (Boston: Beacon Press, 1995), *Ordinary Time* (Boston: Beacon Press, 1993), *Plaintext* (Tucson: University of Arizona Press, 1986), *Remembering the Bone House* (Boston: Beacon Press, 1995), and *Waist-High in the World* (Boston: Beacon Press, 1996); Audre Lorde, *The Cancer Journals*, 2nd ed. (San Francisco: Aunt Lute Books, 1980); Eli Clare, *Exile and Pride* (Cambridge, Mass.: South End Press, 1999).

[20] Susan Wendell, *The Rejected Body* (New York: Routledge, 1996); Jenny Morris, *Pride Against Prejudice* (Philadelphia: New Society Publishers, 1991); Thomson, *Extraordinary Bodies*.

[21] Michelle Fine and Adrienne Asch, eds., *Women with Disabilities* (Philadelphia: Temple University Press, 1988).

[22] Nancy L. Eiesland and Don Saliers, eds., *Human Disability and the Service of God* (Nashville: Abingdon), 1998.

[23] Kathy Black, *A Healing Homiletic* (Nashville: Abingdon, 1996).

[24] David A. Pailin, *A Gentle Touch* (London: SPCK, 1992)

Feminist writings on theology of bodies serve as a springboard for examining

some of the issues raised by the experience of living with dis/abilities and by cultural

assumptions. Theologian Elisabeth Moltmann-Wendel, in *I Am My Body: New Ways of*

Embodiment, analyzes Western Christianity's devaluation of the body, especially

women's bodies, and offers a theology of embodiment rooted in the Jesus movement and

in women's experience.[25] Though acknowledging that some women live with

dis/abilities, she does not include their experience in formulating her theology of

embodiment and suggests other works are needed. In their "body-based theology," Lisa

Isherwood and Elizabeth Stuart acknowledge the complexity and diversity of the body in

Christian theologies and in women's experience.[26]

A fourth set of resources consists of object relations theories about the importance

of mirroring. D.W. Winnicott and Heinz Kohut are my chief conversation partners about

the early childhood experience of mirroring and its relationship to knowledge of self in

adulthood.[27]

Scope and limitations

My focus is on women who happen to experience life with visible physical

dis/abilities. I emphasize women with noticeable dis/abilities, especially those involving

limits of mobility, because their bodily form makes them most prone to being identified

as "different," characterized by society's conceptions of dis/ability, and most likely to

have experience with stares. However, the category "dis/ability" as popularly used is

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[25] Elisabeth Moltmann-Wendel, *I Am My Body* (New York: Continuum, 1995).

[26] Lisa Isherwood and Elisabeth Stuart, *Introducing Body Theology* (Sheffield, England: Sheffield Academic Press, 1998).

[27] D.W. Winnicott, "Mirror-role of Mother and Family in Child Development," in *Playing and Reality* (New York: Basic Books, 1971; reprint, New York: Routledge, 1989), 111-18; Heinz Kohut, *The Analysis of the Self* (New York: International Universities Press, 1971).

extremely broad and includes a wide variety of bodily differences—sensory impairment, intellectual or emotional functioning, invisible disabilities, chronic illnesses, even disfigurement (which involves no inherent lack of ability). Similarly, people with dis/abilities include not just young and mid-life women, but also men, children, adolescents, and elderly folks. People with dis/abilities include not just those who care for themselves but also those who require assistance with daily care. The narratives of people in each of these groups would be worthy of study. Nonetheless, they are not included here. This dissertation focuses exclusively on women with visible physical dis/abilities who care for themselves. The women with whom I spoke had lived with dis/ability for at least five years. Dis/ability was not a new experience in their lives. The lives and concerns of women recently disabled could be quite different and the topic for another study.

I am researching women with dis/abilities in current day United States. Dis/ability has different meanings in other cultures, in different parts of the world, and in different time periods. A cultural comparison of the lives of women with dis/abilities would be fascinating research, but it is not a part of this dissertation, nor is an historical look at women with dis/abilities over the centuries.

When I refer to pastoral care or ministries of care, I understand them to encompass a very broad meaning of care. I am not writing about specific types of care, such as hospital ministry or pastoral counseling. I am also not thinking of care only to specific individuals. Rather, pastoral care is offered in multiple settings to individuals, groups, or communities. Ministries of care informed by the experience of women with dis/abilities can be offered to nondisabled people as well as people with dis/abilities. My

goal is not to pathologize women with dis/abilities. Rather, I am interested in looking for the strengths of women who live in a culture not designed—architecturally or attitudinally—with dis/ability in mind. Neither is it my intent to idealize women with dis/abilities. Popular cultural images often portray people with dis/abilities as either tragic or heroic, but those are one-dimensional and simplistic pictures of complex lives. Finally, this work looks at the experiences of particular persons and, therefore, should not be universalized, though the internal and interpersonal dynamics and responses, as well as the theological and psychological foundations of resistance, may be instructive in understanding the experiences and circumstances of other individuals.

Chapter Outlines

Chapter 2 discusses terminology related to dis/ability, outlines three major models of dis/ability—moral, medical, and social political—reviews the pastoral care and counseling literature related to dis/ability, and states my interest in this topic.

Chapter 3 begins with a brief explanation of the concepts of dominant and alternative knowledges as understood by practitioners of narrative therapy. The lives of women with visible dis/abilities offer alternative, and often contradictory, knowledges to dominant narratives about living with a dis/ability in contemporary culture of the United States. Embedded within the narratives of women with dis/abilities are stories of the stare. I present synopses of my interviews, each of which focuses on the significance of the stare in an individual's experience, confrontation with cultural assumptions, the influence of religious beliefs on her life, and the ways each lives her life independent of or contrary to dominant societal views. A statement of the need to rethink embodiment based on narratives about living with dis/ability closes the chapter.

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With the narratives of women with dis/abilities at the center of this dissertation,

the chapters that follow the narratives approach staring encounters from a variety

perspectives. They progress from a focus on cultural influences and consequences in

Chapters 4 and 5 to interpersonal interactions as mirroring in Chapter 6 to individual

dynamics and responses in Chapters 7 and 8.

More specifically, Chapters 4 and 5 consider the troubling relationship between

the lives of women with noticeable physical dis/abilities and contemporary cultural

assumptions. Chapter 4 explores appearance as a factor in cultural constructions of

"dis/ability" and "woman." Appearance is core to scientific and popular cultures'

assessment of "normal." The high value ascribed to concepts of normalcy serves to

devalue bodies with dis/abilities. The stare symbolizes and reinforces this inferior status.

Alternative biblical narratives proclaiming the goodness of all bodies challenge any

hierarchy of bodies. Bodies are good, because God created bodies good, and because

they are sufficient for living into the fullness of life. However, the value of women most

often is governed by consumer culture's idealized codes of beauty. The presence of a

visible physical dis/ability complicates life for women influenced by these cultural

standards of attractiveness, because dis/ability, by definition, puts one outside the bounds

of "normal" and outside acceptable standards of attractiveness for women.

The consequence of the stare's assignment of inferiority to people with

dis/abilities is the threat of annihilation. Chapter 5 discusses three types of annihilations

that women with dis/abilities face and avenues of resistance they take. First, literal

physical annihilation is threatened when nondisabled people believe that death is

preferable to dis/ability and disablement is a prime argument to support selective

abortion, withholding of medical treatment, assisted suicide, and "mercy" killings. Most people with dis/abilities insist that their lives are very much worth living. Second, women with dis/abilities face annihilation as persons of value due to their bodily configuration. Persons with atypical bodies are sometimes seen as less than human. However, the women I interviewed claim inherent value and resist diminishment. Third, women with dis/abilities face the threat of annihilation as women. Dis/ability functions to overshadow all other characteristics, including gender, in the cultural mind. Women with dis/abilities often are invalidated as suitable partners, mothers, or employees. Some women protest by doing the very thing the culture does not think possible.

The stare re-presents cultural attitudes about dis/ability through interpersonal interactions. Whenever a woman with a dis/ability in the course of common human interaction comes face to face with the socially constructed category of "disabled woman" in the eyes of another, the result is a type of social mirroring that reflects a distorted image based upon a cultural representation and not the particularities of the woman herself. Chapter 6 discusses the psychoanalytic concept of mirroring, the stare as failed mirroring, and possible origins of distorted images. I analyze a particular staring encounter through the lens of the concept of mirroring. Affirming relationships that mirror a woman's known self, as opposed to cultural representations, lessen the wound and aid in recovery. The loving gaze of God is one source of accurate mirroring.

Chapter 7 and 8 take a closer look at staring encounters from the perspective of the women with dis/abilities whose stories I collected. These chapters also consider the role of ministries of care in promoting justice and well-being for people with and without dis/abilities and communities of faith. Chapter 7 focuses on the internal dynamics

triggered by being the object of the stare. This chapter also suggests aspects of care that may be important for a liberating and transformative pastoral practice. Three internal reactions emerge from women's narratives about confrontations with the stare. First, women with dis/abilities can experience a striking clash of realities between the perceptions of the person who stares at them and their own self-understanding. Second, in the facing of a stare, internalized ableism can rise to the surface. That is, a woman with a dis/ability may in fact perceive herself to be as disturbing as the culture images her. Third, the women experience an inner protest, either during or after such encounters. They have a sense that what was amiss in the interaction was not a problem within themselves but coming from something in the other person.

Chapter 8 explores the major types of responses to a devaluing stare that emerge from the narratives. Seven responses stand out. Retreating to a place of safety can give a woman the space and time needed to restore her emotional and mental equilibrium following a hurtful episode. Some women respond to attention targeting their dis/ability by turning the tables, that is, reversing the scrutiny. A woman with a dis/ability may tell her story, expressing her thoughts and feelings about a devaluing encounter. In a situation in which a woman believes the picture mirrored back to her is inaccurate, she may respond by speaking up to challenge others' assessment of her body's limitations and needs. The reverse side of focusing on a woman's dis/ability is ignoring her presence completely—not noticing the woman with a visible dis/ability waiting in line and taking the place in front of her, or not seeing the woman using a chair trying to get to the curb cut in the sidewalk and blocking her way. A woman may respond by expecting the same respect as any other person and communicating her expectation of keeping her place in

line and her need to use the curb cut. Another response to people who stare is to educate—to give them an opportunity to learn about a life lived with dis/ability through words and through actions. Finally, by internally turning off the power the stare has to shame, humiliate, or control, a woman can turn on the power to go about the business of living her own life and writing an alternative narrative about dis/ability.

Chapter 9 presents a summary of the argument and notes areas for further research.

CHAPTER 2

TALKING ABOUT DIS/ABILITY

In this chapter, I discuss four issues concerning dis/ability that lay a

foundation for my exploration of the stare in later chapters—disablement terminology,

models of disability, a review of literature related to physical dis/ability and Christian

pastoral practices, and my social location relative to this study.

Disablement Terminology[1]

The group of people whose insights and experiences are the focus of my research

are women with visible dis/abilities. Essayist Nancy Mairs gives some clues to detecting

a person with a visible dis/ability when she describes herself as having

> certain distinctive, though not unique, features: I am a forty-three-year-old woman
> crippled by multiple sclerosis; although I can still totter short distances with the
> aid of a brace and a cane, more and more of the time I ride in a wheelchair.
> Because of thèse appliances and my peculiar gait, I'm easy to spot even in a
> crowd.[2]

While we do not lack words and phrases to categorize women who are "easy to

spot even in a crowd," the words we use are problematic and controversial. There is no

general agreement about appropriate terminology for referring to people whose bodies

are noticeable due to distinctive physical characteristics. At least three factors contribute

to this lack of consensus—confusion, negative valuation, and personal preference.

Confusion

Confusion exists over the meaning of some terms. The same word can be defined

differently depending upon the individual using the term and the framework of dis/ability

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[1] Jerome E. Bickenbach identifies "disablement" as an artificial, but useful, term which includes a
variety of dimensions and definitions of the categorization of disability. See *Physical Disability and Social
Policy* (Toronto: University of Toronto Press, 1993), 10.

[2] Nancy Mairs, *Carnal Acts* (Boston: Beacon Press, 1995), 31.

out of which that person works. For example, the word "disability" has multiple meanings. Some people use "disability" to mean "any limitation . . . in the ability to perform any activity considered normal for a human being or required for some recognized social role or occupation."[3] This definition comes out of the "medical model of disability." In this model, the body is the site of disability, which refers to a lack in one's capacity to do something deemed valuable by society or an employer. It has to do with what is called a "functional limitation."

"Disability" is also defined as "a product of interactive features of the individual and the environment."[4] The environment referred to in this definition is more than one's physical surroundings—it includes architectural environment, social institutions, and attitudinal environment.[5] This second definition grows out of the "social-political model of disability," which locates the problem of dis/ability within society. In other words, the systems by which society organizes itself are disabling to persons with physical variations because of architectural, institutional, and attitudinal barriers.[6]

There is yet another definition worth adding to the mix. Literary and dis/ability scholar Rosemarie Garland Thomson defines disability as "the attribution of corporeal deviance." She goes on to say that disability is "not so much a property of bodies as a

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[3] Bickenbach, 10. This definition is based on the 1980 publication of the World Health Organization entitled *International Classification of Impairments, Disabilities and Handicaps (ICIDH)*. "Disability" is one of a trio of words used in the classification of disablement. "Impairment" identifies a physical difference, noticeable or not, major or minor. An impairment may or may not become a disability. The third term "handicap" refers to the disadvantage a person faces due to an impairment or a disability. Bickenbach examines these terms in depth, 30-58.

[4] Harlan Hahn, "Civil Rights for Disabled Americans," in *Images of the Disabled, Disabling Images*, ed. Alan Gartner and Tom Joe (New York: Praeger, 1987), 186-87.

[5] Hahn, "Civil Rights," 182.

[6] "Disability" is one of two terms used in the social-political model of disability. This model also uses "impairment" to indicate the particular biological features of an individual. See Bill Hughes, "The Constitution of Impairment: Modernity and the Aesthetic of Oppression," *Disability and Society* 14, no.2 (1999): 155-72 for a view which challenges the use of the term "impairment" in the social-political model of disability.

product of cultural rules about what bodies should be or do."[7] Still within the social-political framework, her definition builds on one of this model's several ancestors—deviance theory.[8] Deviance is the quality ascribed to someone who fails to live up to society's norms.[9] In other words, society has constructed an idea of what a body must look like and how a body must function. Anything outside of these limits is considered deviant, not just different, but transgressing the norms of bodily form.

When I use the word "dis/ability," it is Thomson's definition, mixed with Mairs' reference to herself as "easy to spot even in a crowd," that describes most nearly what I have in mind. Both Thomson's and Mairs' insights highlight a focus on visible bodily differences. I use the term "women with dis/abilities" with the awareness that the understanding of "dis/ability" by the general public is more closely akin to the medical model which focuses on a "lack" or "inability." To encourage readers who are accustomed to equating "disability" and "unable" to remember that bodily variations co-exist with abilities, I will separate the "dis" from the "abilities" when referring to an individual. Several ways of doing this include (dis)ability, dis/ability, disAbility, all of which serve the purpose. My custom is to use the backward slant—dis/ability.

Negative Valuation

A plethora of words exist to name or describe persons with physical variations—disabled, handicapped, physically-challenged, differently-abled, crippled, blind, deaf, lame, impaired, infirm, invalid, deformed, maimed, and defective, among

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[7] Rosemarie Garland Thomson, *Extraordinary Bodies* (New York: Columbia University Press, 1997), 6.

[8] Bickenbach, 142-49, outlines the role of deviance theory in the social-political model of disability.

[9] Bickenbach, 142.

others. Many of these terms are criticized for being value-laden or euphemistic. Most words used to label people with dis/abilities are loaded with negative value. It is not value-neutral to be termed defective, deformed, or invalid. They are the substance of insult. Poet and essayist Eli Clare writes that, as a child, classmates would taunt her by calling her "defect," "retard," and "monkey" as they threw "rocks and rubber erasers."[10] In times past, the custom was to call people with physical dis/abilities "invalids." A legal document which is in-valid is null and void, without substance, unable to be defended. This term articulates social assumptions that people with dis/abilities are useless.

To counter the negative value of many labels, phrases such as "physically-challenged" or "differently-abled" were created. Some people criticize these as being euphemisms that describe nothing in particular. Nancy Mairs writes of the term "differently-abled" that it

> partakes of the same semantic hopefulness that transformed countries from "undeveloped" to "underdeveloped," then to "less developed," and finally to "developing" nations. People have continued to starve in those countries during the shift. Some realities do not obey the dictates of language.[11]

Words that sound benign do not change the circumstances for people who find themselves in a culture built for nondisabled bodies. Eli Clare has another opinion of euphemistic phrases, pointing out that the only way such phrases would have meaning would be if society were different than it is.

> In the world as it should be, maybe disabled people would be *differently abled*: a world where Braille and audio-recorded editions of books and magazines were a matter of course, and hearing people signed ASL; a world where schools were fully integrated, health care, free and unrationed; a world where universal access meant exactly that; a world where disabled people were not locked up at home or in nursing homes, relegated to sheltered employment and paid sweatshop wages.

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[10] Eli Clare, *Exile and Pride* (Cambridge, Mass.: South End Press, 1999), 68.
[11] Nancy Mairs, "On Being a Cripple," in *Plaintext* (Tucson: University of Arizona Press, 1986), 10. Used by permission of the University of Arizona Press.

But, in the world as it is, *differently abled, physically challenged* tell a wishful lie.[12]

To the extent that these phrases "tell a wishful lie," they encourage people to believe that the world is all right as it is. Therefore, nondisabled people fail to realize the problems and to join persons with dis/abilities in taking action to make the needed changes in our environment so that all persons may participate in society to the fullest extent of their abilities and desires.

Personal Preference

Blanket terms such as "the disabled" or "the handicapped" are both inaccurate and imprecise. They reduce whole groups of people to one feature. A person who is blind, a wheelchair-user, and a person with facial disfigurement are all put in the same category though each faces disparate obstacles and has dissimilar needs. Nonetheless, Clare claims the adjectival form of the term "disabled" to apply to herself and suggests a very interesting parallel word to describe nondisabled people. "But if I call myself disabled in order to describe how the ableist world treats me as a person with cerebral palsy, then shouldn't I call nondisabled people *enabled*?"[13]

Clare raises two important issues here—the language to use for people without dis/abilities and for a society which discriminates because of physicality. Though there are many words to describe people who have dis/abilities, only a few have been used for the people who do not fit into that category. Often they are referred to as "able-bodied" or, in an effort to remind them that aging, accidents, and illnesses are an inevitable part of life, as "temporarily able-bodied." The more frequent term in the latest literature is

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[12] Clare, 69.
[13] Clare, 67.

"nondisabled" which depicts them as an other to people with dis/abilities. "Enabled" highlights their advantage, based on bodily form, in an environment which disadvantages others. The term frequently used to describe society's make-up in which certain persons are enabled and others are not is the one Clare uses above—ableist. Ableism is the noun form.

Personal preference is a major factor in choosing a word to describe oneself. Some persons are reclaiming outdated or discarded, even "politically incorrect" or "tainted," terms. "Cripple" is one of those words. It is rarely used and offensive to many. One of the women I interviewed spit the word out as she spoke it as if it were spoiled food that left a bitter taste in her mouth. The word was distasteful to her for it was filled with unpleasant memories from her childhood. Mairs, on the other hand, claims it for herself, though she states she would never use it to refer to another.

> I am a cripple. I choose this word to name me. I choose from among several possibilities, the most common of which are "handicapped" and "disabled." I made the choice a number of years ago, without thinking, unaware of my motives for doing so. Even now, I'm not sure what those motives are, but I recognize that they are complex and not entirely flattering. People—crippled or not—wince at the word "cripple," as they do not at "handicapped" or "disabled." Perhaps I want them to wince. I want them to see me as a tough customer, one to whom the fates/gods/viruses have not been kind, but who can face the brutal truth of her existence squarely. As a cripple, I swagger.
> But, to be fair to myself, a certain amount of honesty underlies my choice. "Cripple" seems to me a clean word, straightforward and precise. . . . As a lover of words, I like the accuracy with which it describes my condition: I have lost the full use of my limbs.[14]

Mairs reclaims a word that some people detest, because it communicates her strengths in the face of a debilitating illness and other people's reactions, and it describes to her satisfaction the physical manifestations of multiple sclerosis in her body.

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[14] Mairs, *Plaintext*, 9-10. Used by permission of the University of Arizona Press, © 1986.

There are no adequate words to name people with dis/abilities. They all come

loaded with socially inscribed connotations. This is not necessarily because of the words

themselves. As Mairs describes above, some of the most offensive are precise and

accurate. However, if a culture views people with dis/abilities negatively, no matter what

noun or adjective is applied, sooner or later it becomes contaminated by those negative

values.

In the United States, the description with the most currency at the moment is

"people with dis/abilities." It is preferred because of its "people-first" nature. It is also

the term used prominently in the political arena. Therefore, I use the term "women with

dis/abilities," with the understandings I defined and described earlier, as I focus on those

women who are "easy to spot even in a crowd."

Models of Disability

Connected to terminology are the models used to frame an understanding of

dis/ability. Dis/ability advocates and scholars identify three primary models of

dis/ability. The moral model is the oldest model of disability and is, for good reason,

outwardly in disrepute today. Unfortunately, vestiges of it linger. The medical model of

disability is the most extensively used and emphasizes empirical knowledge and

scientific explanations.[15] The social-political model of disability has gained prominence

over the past several decades, especially among persons with dis/abilities. It has been,

and is, a major force behind much activism and advocacy by persons with dis/abilities in

the struggle for civil rights.

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[15] Another model of disability, mentioned in public policy literature, is the economical model. It joins the medical model in a focus on the functional limitations of people with disabilities but is more interested in the effects of physical limitations on employment possibilities and governmental financial assistance than in medical issues. See Bickenback, 93-134.

The Moral Model of Disability

One framework for understanding the phenomenon of disability connects physical attributes to moral qualities—physical "imperfections" are viewed as signs of moral flaws. It is assumed that the individual with a dis/ability or her family has violated a moral boundary. The visible physical feature is the manifestation of a previous transgression. An example of this physical-moral connection appeared recently in the guise of a "blessing" printed in a feminist, church-related, publication:

> May those who love you
> Love you,
> And those who don't love you
> May God turn their hearts
> And if God doesn't turn
> Their hearts
> May God turn their ankles
> That you may know them
> By their limping.[16]

This supposedly humorous "blessing" associates individuals with visible injuries or impairments (limping) with persons who are not kindly disposed toward the one receiving the "blessing" (those who don't love you). This saying warns that physical features reflect the state of the heart of a particular individual. The Divine is even implicated as being a part of the scheme, marking certain individuals as signs to others of potential malevolence or, at least, a lack of benevolence.

Religious significance can be attached to dis/ability in other ways. Some suspect diabolical rather than divine forces at work. When Diane DeVries was born without limbs, her grandmother organized a séance "at which Diane's mother was accused of

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[16] *Illuminations: Newsletter of the Voices of Sophia*, Summer 2000, 4. It is referenced as coming from "Keeping the Faith," though no additional information is given. Rhonda Olkin, in *What Psychotherapists Should Know about Disability* (New York: Guildford Press, 1999), 25, indicates that she found the same saying on a "Gaelic blessing plaque" advertised in a mail-order catalogue, *Wireless*.

having fornicated with Satan."[17] A child with a dis/ability was considered to be a child of the devil. Diane's parents moved to another state to remove that negative influence from her life.

Physical changes from a slow growing tumor on the lining of his spinal column precipitated anthropologist Robert Murphy's fieldwork in the world of people with dis/abilities. He suggests a hidden moral dimension to disability when he refers to the "haunting, never-articulated question [asked by disabled persons]: What did I do to deserve this?" This unspoken riddle reveals, Murphy posits, a reversal of the typical order of events surrounding crime and punishment. The usual sequence "goes from wrongful act to guilt to shame to punishment." In the case of disability and other unexpected or distressing events, however, the chain of events is reversed and "goes from punishment (the impairment) to shame to guilt and, finally, the crime."[18] The assumption is that some wrong must have been done for a disability to occur and that the dis/ability is deserved. Disability in the present is the obvious factor; but the past action is a puzzlement, "haunting" and unexpressed, though no less certain.

A variation on the theme of wrongful action arises when an illness or a condition persists. Murphy briefly describes sociologist Talcott Parsons' research on the "sick role." Parsons identifies two chief characteristics of the "sick role." First, the individual is temporarily released from her social roles and, second, the person who is ill must do everything in her power to get better. It is the second that concerns us here. Recovery is

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[17] Geyla Frank, "'Becoming the Other': Empathy and Biographical Interpretation," *Biography* 8 (1985): 203.

[18] Robert F. Murphy, *The Body Silent* (New York: W.W. Norton, 1990), 93.

the only option, permanence is not.[19] The implication is that, if one has an illness or condition which does not go away, one has not done everything to get better. One has not tried hard enough, or not sought or followed the proper medical advice, or one is a malingerer. Any failure to improve is blamed on the patient.[20] The connection between righteousness and physicality holds fast.

Textual interpretations of Christian scripture linking cure and faith strengthen the connection between physical ailments and moral transgressions. A person's faith plays a part in the evangelists' portrayal of many of the healing miracles performed by Jesus. Jesus is reported to have said "Your faith has made you well." Some Christians believe that faith can cure all diseases and dis/abilities and, therefore, the absence of healing is due to insufficient faith.

The Medical Model of Disability

Medical views have a place of priority in what people in scientific cultures believe about the world and about human beings. It is not surprising that people turn to science and medicine with their questions about disability, nor that these fields have much to say in reply. The medical model of disability, like the moral model, focuses on the individual. The problem is identified with the person who exhibits some difference from the typical body. Something is physically "wrong" with the individual. In this model, disablement is not primarily a moral flaw but a biological one. Jerome Bickenbach, whose expertise is in social policy, explains the premise behind the medical model.

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[19] Murphy, 19, citing Talcott Parsons, "Definitions of Health and Illness in the Light of American Values and Social Structure," in *Patients, Physicians and Health*, ed. E. G. Jaco (Glencoe, Ill.: Free Press, 1998); and Talcott Parsons, *Social Structure and Personality* (New York: Free Press of Glencoe, 1964).
[20] Murphy, 51-52.

> The most commonly held belief about disablement is that it involves a defect, deficiency, dysfunction, abnormality, failing, or medical 'problem' that is located in an individual. We think it is so obvious as to be beyond serious dispute that disablement is a characteristic of a *defective person*, someone who is functionally limited or anatomically abnormal, diseased, or pathoanatomical, someone who is neither whole nor healthy, fit nor flourishing, someone who is biologically inferior or subnormal.[21]

Harlan Hahn, a political scientist and dis/ability studies scholar, refers to this type of framework as a "functional limitations model" because of the emphasis put on activities a person cannot do.[22]

Nonetheless, the medical model represents an advancement over the moral model in its assessment and treatment of dis/ability. The medical community provides significant resources to people with dis/abilities. Medical professionals offer people with dis/abilities more options in living their lives through modifications in the physical environment or in the body. Results include increased functioning and greater independence, highly valued states in an industrial society.

One widely-used set of definitions about disablement developed out of this framework. In its efforts to assess health care systems, the World Health Organization (WHO) values uniformity in the terms used to describe disablement.[23] The three categories of disablement the WHO uses are *impairment, disability*, and *handicap*. These terms attempt to contrast and distinguish among a physical anomaly, a limitation, and social barriers related to the physical form of an individual. Disablement assumes a comparison with a "normal," healthy body throughout life, therefore, *impairment* is

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[21] Bickenbach, 61.

[22] Hahn, "Civil Rights," 183.

[23] Bickenbach, 23.

defined as "any abnormality of physiological or anatomical structure or function."[24]

According to this definition, a person who is unusually tall, one whose hair grays at an

early age, or a person with multiple sclerosis are all persons with impairments. Under

this system, to label a physical feature as an impairment supposedly has no negative

connotations or social implications, and merely notes a biological difference, which may

or may not have a large impact on the life of the individual.

An impairment becomes a *disability* when it limits an individual's ability to

assume activities or roles considered normal for a person of a given age, gender, social

position, and so forth in a particular context.[25] Not all impairments are disabilities, but

disabilities are based on having an impairment that is restrictive in some way.

"Disabilities affect capabilities, what people actually can do or become."[26] In this model,

an impairment or a disability is also a *handicap* when the individual encounters social

disadvantage due to the presence of a certain physical feature.[27]

Medical and scientific communities have several goals regarding

dis/ability—identify the abnormality, determine the cause, and develop a course of action

for correcting or eliminating the disability by, for example, altering a gene, medicating

symptoms, removing the offending body part, aborting a fetus. Failing a cure, medical

personnel seek to help persons with dis/abilities navigate an inhospitable physical

environment. Many in the field dedicate themselves to making daily activities easier for

people with dis/abilities through strengthening the body, discovering new ways to

accomplish a task when the old ways no longer are effective, or adapting the body so that

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[24] Bickenbach, 10.
[25] Bickenbach, 36-37.
[26] Bickenbach, 37.
[27] Bickenbach, 48.

it can approximate normal functioning. Unfortunately, the side-effects of this help are not always benign. As one person with a dis/ability pointed out, the plan is to try "to make you less like yourself and more like the able-bodied."[28]

Another problematic feature of the medical model is that it establishes a hierarchy between practitioners and patients. There are experts and those who seek that expertise. The medical experts act; the patients are acted upon. Patients are the objects of surveillance, multiple tests, and numerous instances of poking and prodding, pushing and pulling, scraping and tapping. For people with dis/abilities, this may go on, over and over, throughout their lifetime. The patients are told what the experts have decided is the truth about the patients' bodies. The system encourages infantilization. The experts develop a course of treatment; the patients are expected to follow it with little or no question. At this point, the moral and medical models converge. Rejecting medical advice, refusing to relinquish one's own expertise about and experience of one's body, or determining one's own course of treatment all put one at odds with the required subservient position of the patient, so that when treatment fails, which with permanent disability is inevitable, it becomes the patient's fault. She is the one who has failed.

The Social-Political Model of Disability[29]

In the social-political model of disability, disability is not an individual problem, a feature of a particular body. Society is the site of the problem of dis/ability. This is different than the medical model's concept of "handicap." The social disadvantage of a

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[28] M. Mason, "Internalised Oppression," in *Disability Equality in the Classroom: A Human Rights Issues*, ed. R. Reiser and M. Mason (London: Disability Equality in Education, 1992), 27, as quoted by Deborah Marks in *Disability: Controversial Debates and Psychosocial Perspectives* (London: Routledge, 1999), 69.

[29] The social-political model also is frequently called the social model of disability or the minority model of disability.

"handicap" is due to the body's configuration. In the social political model, society's

configuration causes the disadvantages faced by persons with dis/abilities. Society is

organized so that nondisabled people are advantaged or "enabled" in ways that exclude

people with dis/abilities who are, thereby, dis*en*abled.[30] Contrary to the theories of the

medical model, that people with dis/abilities are disadvantaged because their bodies

cannot do something essential, the social political model claims that dis/ability is a

socially constructed category. That is, certain characteristics, limitations, and perhaps

even a few questionable privileges (receiving charity, for example) are expected of

people placed into the dis/ability category. These expectations are based more on the

dis/ability category than on any particular personal trait.

> [T]here is a range of disadvantages and limitations that have everything to do with how people react—their attitudes and their behaviour—and nothing to do with one's incapacities. To say that disadvantages are socially constructed means that these experiences could be altered, remedied, or ameliorated without making any change in the physical condition of the individual.[31]

The social-political model utilizes deviance theory.[32] A person who fails to live

up to or deviates from society's often unwritten rules about human appearance or

behavior is characterized by her difference. In the eyes of culture, a woman's bodily

configuration defines her. Psychologist and dis/ability rights activist Adrienne Asch

records an incident in her life when, as part of an exercise at a professional conference,

she had to choose one label with which to identify. Though she had multiple and

appropriate choices, she eventually decided to stand under the sign marked "disability,"

in part because no one else was there. An acquaintance, upon hearing that Asch had

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[30] Clare, 67, uses "enabled" to describe nondisabled people.

[31] Bickenbach, 136-37.

[32] See discussion of deviance theory in the section on Disablement Terminology above.

difficulty deciding, made a remark indicating that the acquaintance thought that the dis/ability identity was the only one Asch could have selected.[33] In the view of this acquaintance, Asch's blindness was the feature that defined her.

Hahn relies on a minority group framework where "prejudice and discrimination [are] the major issues confronting citizens with disabilities . . . . the primary source of the problem [confronting people with dis/abilities] can be traced to defects in what might be termed the attitudinal environment of society rather than to personal deficiencies."[34] Therefore, social arrangements are disabling, not bodies. Bodies may have incapacities and limitations, but the real barriers are found in the physical environment and the attitudes of the nondisabled majority. Attitudes, in fact, may be the greater problem, as it is generally accepted assumptions about people and their bodies that lie behind both architectural design and governmental policies.[35] Therefore, a person with a dis/ability is someone who faces a disabling social system.

The social political model offers a vision of society where everyone is included, every member of society has a place—not unlike the Christian vision of the church, the Body of Christ. The purposeful exclusion of people with dis/abilities, though perhaps not as overtly violent as with other minorities, is a justice issue in this model. What begins as a critique of the way society organizes and perpetuates itself becomes a political matter. People with diverse dis/abilities are beginning to act as a cohesive group to work for social change through political means.

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[33] Adrienne Asch, "Personal Reflections," *American Psychologist* 39, no. 5 (May 1984): 551-52.
[34] Hahn, "Civil Rights," 184.
[35] Hahn, "Civil Rights," 193.

Literature Review

These three models of disability provide a framework for the literature review.

The scholarly literature most directly related to this dissertation concerns itself with the

intersection of pastoral theology, care, and counseling and physical dis/ability. The

literature in this area is sparse. Therefore, I expand the boundaries somewhat and include

a few books in fields such as doctrinal theology and physical dis/ability, or ministry and

physical dis/ability.[36]

Moral Model of Disability

No scholars currently writing in pastoral theology, care, and counseling claim the

moral model of disability. In fact, writers are explicit about denying a belief in any

connection between dis/ability and moral failure. Most works contain brief sections

repudiating such ideas. One book, however, argues in detail from a doctrinal theological

point of view, against any innate association between sin and dis/ability or between

divine agency and dis/ability. In *A Gentle Touch: From a Theology of Handicap to a*

Theology of Human Being, process theologian David A. Pailin dismantles the classic

Christian theological arguments for linking divine activity with dis/ability.[37] He suggests

that such arguments were formulated in an attempt to make meaning of human situations.

People want to know "that in the end things really do make sense—and make sense in

terms of the purpose of one who is holy, ultimate, perfect and indestructible."[38]

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[36] Not included is literature related to cognitive dis/abilities, such as Brett Webb-Mitchell, *Dancing with Disabilities* (Cleveland: United Church Press, 1996), or psychiatric diagnoses, for example, Stewart D. Govig, *Souls Are Made of Endurance: Surviving Mental Illness in the Family* (Louisville: Westminster John Knox Press, 1994).

[37] David A. Pailin, *A Gentle Touch: From a Theology of Handicap to a Theology of Human Being* (London: SPCK, 1992).

[38] Pailin, 69.

Pailin proposes that making sense of unexpected or unwelcome situations does not necessitate believing that God controls every event like a puppeteer pulling all the strings of the creatures attached.[39] He denies that dis/abilities can be traced to divine activity, arguing that dis/abilities are not punishments for the sin of the individual or the sins of others.[40] They are not tests of character concocted by God, neither are they opportunities for the personal development of those who care for persons with dis/abilities.[41] Pailin argues that the Divine does not plan and execute everything that happens. Other factors at work in the world contribute to the occurrence of dis/ability. "Many events are the outworking of regular patterns of natural behaviour ('the laws of nature'), others (particularly at the quantum level) happen by chance, and some are the result of choices made by conscious agents." [42]

Pailin began his work with the intention of writing a theology of handicap but, instead, ended up with a theology of human being, as the sub-title indicates. He concluded that any condition that society labels as dis/ability is not a special state of being but one of the many variations of being human. To be human is to be finite.[43] That a particular finitude may be recognized in persons with noticeable dis/abilities and labeled by nondisabled people does not mean people with dis/abilities are marked by finiteness while nondisabled people are not.

Furthermore, he claims that the presence or absence of dis/ability does not alter the divine inclination toward the human. The value of each human life is the same,

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[39] Pailin, 70.
[40] Pailin, 77-78.
[41] Pailin, 79-80.
[42] Pailin, 183.
[43] Pailin, 186.

because human worth is not based on what one can do but on what one is—loved by God. "The fundamental worth of each human being—and indeed of everything that exists—lies neither in what a person achieves nor in what a person makes possible for others to achieve, but in God's love for that person."[44] The purpose of each human life is also the same—to live abundantly, into the fullness of life. "[T]he goal must be that each handicapped person—and indeed every person—be helped to live as full a life as is practicable."[45]

Pailin's assessment and redefinition of theological issues related to dis/ability is helpful to my work. Breaking the long-standing theological connection between dis/ability and punishment for sin, tests of character, or personal growth lays the groundwork for challenging discriminatory attitudes against people with dis/abilities. Effective ministries of care with, by, and for persons with dis/abilities are based on a theological framework that advances just treatment and well-being for all persons, with and without dis/abilities. Pailin offers such a framework. The women I interviewed, and the many more women and men with dis/abilities whose works I read, consistently indicate that society's negative attitudes are more formidable barriers than any physical characteristic.

Pailin's assertion that finiteness is a characteristic of all humans makes impossible the attribution of limitations primarily to people with dis/abilities. The presence of dis/abilities does not indicate a sub-category of humans, or a category of sub-humans. Rather, dis/ability is one of many variations in the human body. Too often people with dis/abilities are valued less than nondisabled people. I explore some consequences of this

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[44] Pailin, 95.
[45] Pailin, 110.

"less than" thinking in later chapters, where I also examine the theory that people with dis/abilities are targets for the projection of nondisabled persons' unwanted and unacknowledged limitations.

<div align="center">Medical Model of Disability</div>

The majority of pastoral care and counseling literature assumes the medical model of disability. Often written by and for persons working in rehabilitation or hospital settings, the emphasis is on the important task of helping people who are recently disabled adjust to a new life.

In *Invisible Barriers: Pastoral Care with Physically Disabled People*, Jessie van Dongen-Garrad positions herself squarely within the medical model of dis/ability and utilizes the disablement categories of the World Health Organization.[46] For her, the problems associated with having a dis/ability are located within persons' bodies. The way society is organized may have an impact on persons who live with dis/abilities, but this is secondary to or derivative of any physical limitations. It is the disabled body that causes difficulties for an individual, because the body with a dis/ability cannot perform some, or many, of the "essential activities of daily life" that nondisabled people are able to do.[47] The aim, therefore, of helping professionals is to promote the physical and emotional adjustment of the person with a dis/ability to her body and the realities of society.

Dongan-Gerrad sees a relationship between emotional well-being and dis/ability. Lack of emotional well-being, especially diminishment in one's sense of worth, makes

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[46] Jessie van Dongen-Garrad, *Invisible Barriers: Pastoral Care with Physically Disabled People* (London: SPCK, 1983).
[47] Dongen-Garrad, 13-14.

rehabilitation more difficult. According to her studies, about half of all women and men with dis/abilities (as compared to nondisabled women and men) "show signs of emotional disturbance," which generally "develops after the onset of disability and . . . is a reaction to the state of being disabled."[48] Some of the signs of emotional disturbance the author notes in people with dis/abilities are depression, hostility, and repression of feelings.[49] Dongen-Garrad does not explore the effects negative cultural attitudes toward persons with dis/abilities may have on one's emotional well-being. Rather, she hypothesizes that chronic grief over the condition of being disabled may lead to emotional disturbance.[50]

Dongan-Garrad offers several examples of people with dis/abilities with whom she has worked, noting in particular the degree of their capacity to adapt and adjust and their attitudes about physical changes in their bodies. One person, " Mary Hamilton," who experienced considerable anxiety and many changes in her life and body, worked cooperatively with her rehabilitation team and made a relatively smooth and successful, though lengthy, adaptation to the demands of her impairments, disability, and handicap. Accordingly, Mary is offered as a good example of what is possible with the right attitude and sufficient support.[51]

Dongan-Garrad describes another individual, "Mr. Roberts," as having a poor attitude and lacking in self-esteem. He became discouraged, disillusioned, and bitter when medical professionals were unable to diagnose his disorder for over a year. Once diagnosed properly, he received appropriate treatment and recovered physically, but he

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[48] Dongen-Garrad, 57, 58.
[49] Dongen-Garrad, 56-58.
[50] Dongen-Garrad, 71.
[51] Dongen-Garrad, 7-10.

remained angry and hostile toward the medical establishment. Mr. Roberts "was not able to make a full readjustment afterwards."[52]

Dongen-Garrad is not unaware of nor unconcerned about the prejudicial attitudes of nondisabled people toward people with dis/abilities. She advocates for reciprocal relationships between nondisabled people and persons with dis/abilities. She acknowledges the disruption cultural attitudes can cause in the lives of people with dis/abilities, but believes that encouraging societal change alone is not adequate to address the needs of persons with dis/abilities.

Dongen-Garrad and I are both interested in the well-being of persons with dis/abilities though our emphases are different. She writes from her work in rehabilitation settings with persons who are newly disabled. I am interested in the experiences of women who have lived with a dis/ability for a number of years and who do not live in an institution but are making their way through life in society. Because of her setting, she is naturally invested in the medical model of disability. I am looking through the lens of the social political model of dis/ability at the ways negative cultural values and assumptions about dis/ability compromise the lives of women with dis/abilities. I also believe that, by hearing their experiences, we in communities of faith and in the field of pastoral theology, care, and counseling can learn from the experiences, strengths, and challenges of women with dis/abilities in order to be better equipped to promote not only adjustment but also justice for and the well-being of women and men who live with dis/abilities and the communities to which they belong.

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[52] Dongen-Garrad, 26.

Dongen-Garrad is right that changing society will not solve all the problems

newly disabled people face. However, failing to address adequately negative cultural

attitudes will greatly increase physical, emotional, spiritual, and architectural challenges,

whether the onset of dis/ability was recent or a part of life before birth.

Also within the medical model of disability is *Coping with Physical Disability* by

Jan Cox-Gedmark, who writes from the perspective of a chaplain for a rehabilitation

facility.[53] Her audience seems to be persons who have recently experienced a life-

changing injury or illness. Characteristic of the medical model, it is the individual with

the injury or illness and family members who need to learn to cope, accept, and adjust.

Cox-Gedmark essentially writes a self-help book. The emphasis is put on the individual

and what each one can do in an unexpected situation. She focuses on the physical,

emotional, and spiritual problems an individual might face.

Her suggestions are practical and may well be helpful to persons whose life has

recently changed drastically due to serious injury or illness. Theologically, she affirms

the steadfastness of God as the individual and family members deal with life changes.

She affirms that God's creative powers continue to be at work in peoples' lives. She

encourages forthrightness in expressing one's feelings, even angry feelings, to God.

Cox-Gedmark affirms the value, wholeness, and abilities of each person, though

she recognizes that others may not do the same. She briefly acknowledges society's role

in creating barriers for people with dis/abilities and spends a short section on attitudinal

barriers, including stares, in society. Through her own comments and personal

statements by others, the book offers suggestions for handling stares: take the initiative in

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[53] Jan Cox-Gedmark, *Coping with Physical Disability*, (Philadelphia: Westminster Press, 1980).

meeting others; act in a way that does not alienate another; use humor; go out in public with friends who accept you as you are; and go where you want to go regardless of what others think, say, or do.[54] She encourages people with dis/abilities to live life fully on their own terms.

Cox-Gedmark and I have several points of agreement. Both of us are interested in ministries of care with people with dis/abilities. Both of us affirm the wholeness, capabilities, and worth of people with dis/abilities. Both of us are concerned about attitudinal barriers faced by people with dis/abilities. We both look for the activity of God in the lives of persons rather than in their bodily configuration.

However, my approach and purpose is different than hers. I approach the problems that people with dis/abilities face from the perspective of cultural structure, attitudes, and values. Living with physical limitations is worsened by distancing attitudes and an unwelcoming environment. The purpose of my work is to make others aware of the barriers created by negative cultural assumptions about dis/ability and the possibility of new ways to look at women and dis/ability that emerge from their lives and stories. Whereas her readers are newly disabled persons, I am interested in communicating with people in ministries of care and communities of faith about effective and ineffective spiritual care and helpful and harmful interpersonal and communal relationships.

A volume edited by Roy E. Hartbauer, *Pastoral Care of the Handicapped*, is in the same genre as the two books reviewed above.[55] The essays cover a number of topics, including some pertaining to specific dis/abilities. Hartbauer himself is the author of

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[54] Cox-Gedmark, 95-97.

[55] Roy E. Hartbauer, ed., *Pastoral Care of the Handicapped* (Berrien Springs, Mich.: Andrews University Press, 1983).

several of the essays. In the first two chapters, he lays out his expectations for the counselors of persons with dis/abilities and his assumptions about "the handicapped" who might be coming to see a parish pastor. He imagines that the situation precipitating the counseling is the "trauma" of the "onset or discovery of a handicap."[56] Either the individual with a dis/ability or a family member initiates a visit with the pastor. He anticipates that the "counselee" will be depressed, discouraged, and lacking in a sense of self-worth.[57] (Re)establishing self-worthiness is an important goal he has for the person.

Hartbauer identifies five stages of "self-preservation" that he believes the "afflicted" go through as they learn to accept dis/ability in their lives—truth rejection, responsibility acceptance, suicide potential, aggression, and habilitative participation.[58] The names he assigns the stages are a little unwieldy, but basically he is saying that people confronted with a dis/ability deny its existence, wonder if they have caused it, give up on life, want to blame or destroy someone else, and then do what they have to do to live life the best way they can.

Hartbauer offers the following helpful suggestions for counseling a person with a dis/ability or a family member: Listen well, and accept the person for who they are and where they are.[59] Know yourself—your biases and your limitations as a counselor. Also, your faith must be solid, for a shallow faith will help no one.[60] Affirm the will to live.[61] Let the person with a dis/ability know that sex is a normal part of life. Encourage the

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[56] Hartbauer, 1.
[57] Hartbauer, 19
[58] Hartbauer, 21-24.
[59] Hartbauer, 4-6; 10-12.
[60] Hartbauer, 2-4.
[61] Hartbauer, 6-8.

counselee to strive for self-actualization.[62] Teach the congregation how to be with a person who has a dis/ability—how to confront the congregants' own biases about dis/ability and ways to prepare the physical environment for inclusion of persons with dis/abilities.[63]

Similar to the other books utilizing the medical model, this one assumes pastoral practice in the presence of a recent diagnosis or realization of a dis/ability. Unlike the other books, this one addresses a parish setting and not an institutional setting. The language used to identify people with dis/abilities is off-putting to me. This is largely due to the difference in the era in which each of us is writing. Terms like "the handicapped" or "the afflicted" seem to gather people with all sorts of diverse characteristics into a single, supposedly similar group. They also seem condescending. Nonetheless, the contributors to *Pastoral Care and the Handicapped* and I all are situated in the field of pastoral care and counseling and have the well-being of persons with dis/abilities in mind.

Social Political Model of Disability

Clergyperson Harold H. Wilke, a prominent advocate for persons with dis/abilities, takes a social political approach in *Creating the Caring Congregation*.[64] "It is evident that society itself, with its attitudes and its architecture, is the basic handicapping condition."[65] This short book presents some background material on scripture and dis/ability, churches' reactions against and responses to dis/ability, and practical guidelines for establishing caring congregations, that is, communities of faith

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[62] Hartbauer, 8-10; 13-14.
[63] Hartbauer, 14-16.
[64] Harold H. Wilke, *Creating the Caring Congregation* (Nashville: Abingdon Press, 1980).
[65] Wilke, 16.

that welcome people with dis/abilities. Wilke's short discussion of biblical perspectives on dis/ability emphasizes that neither strength nor beauty bring salvation but the grace of God. Each person is the same before God.

Wilke notes that churches have been both inhospitable and welcoming to people with dis/abilities. Sometimes Christian congregations have rejected those with dis/abilities. At other times and in other places, churches have organized and supported creative programming for and with people with dis/abilities. Wilke identifies some of the marks of a caring congregation, including physically and sensorially accessible buildings and worship, service broadly understood as both binding up wounds and changing social structures, and a commitment to the inclusion of all people. He outlines a practical plan for a congregation to become a caring and healing place for all.

Creating the Caring Congregation emphasizes ways a congregation can intentionally offer ministry to and with persons with disabilities. This dissertation focuses on the lives of women with dis/abilities and the phenomenon of the stare. Wilke reports on people with dis/abilities receiving negative social attention. I investigate factors that contribute to the stare as symbolic of negative cultural attitudes. Wilke's intended outcome is not pastoral care but social action. To me, promoting justice and well-being for persons with dis/abilities is a task of pastoral care. Both of us look forward to a time when fully inclusive congregations are commonplace rather than exceptional.

In *Strong at the Broken Places: Persons with Disabilities and the Church*, Stewart D. Govig weaves stories from the lives of people with dis/abilities with biblical stories in

order to expand the readers' knowledge of what scripture has to say about dis/ability.[66]

The book consists of two parts. In Part1, he takes up the task of "examining broken places." Frequently, though not always, the broken places he examines are cultural attitudes and barriers. People marked by physical, cognitive, or psychiatric dis/abilities are too often pitied and avoided by others. "The reactions of others are the real cripplers."[67]

In Part II, he focuses on transforming elements of Christian faith and community, specifically fellowship, encouragement, ministry, and the promise of redemption. The inclusive community offers fellowship by welcoming strangers, treating newcomers as guests, and giving guests the opportunity to become partners.[68] Both encouragement and ministry are provided to people with dis/abilities and by people with dis/abilities. "[W]e are, after all, interdependent members of the body of Christ, called as equal participants in the church's mission (1 Cor. 12)."[69] The promise of redemption comes not from society's vision of what is good and right and useful but from the divine perspective.

Govig does not minimize the difficulties of being shut out by attitudinal barriers, but in the final analysis, society does not have the last word—God does. In both parts of this book, Govig emphasizes the social attitudes of nondisabled people toward people with dis/abilities. In the first part, his concern is primarily with distancing attitudes and fractures in relationships. The second part suggests ways of being with one another that

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[66] Stewart D. Govig, *Strong at the Broken Places: Persons with Disabilities and the Church* (Louisville: Westminster John Knox Press, 1989).
[67] Govig, 17.
[68] Govig, 77-78.
[69] Govig, 107.

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lead to change. Threaded through both parts is his hope that Christians follow the example of Jesus who welcomed those whom society considered outcasts.

Govig's work is important to mine because he identifies stares as a barrier, an emblem of differences in perceived power, value, and personhood between nondisabled people and people with dis/abilities. He corroborates my hypothesis that the stare is an important facet and symbol of negative attitudes toward people with dis/abilities. However, the stare is not central to his work. I build on the idea of the stare as an attitudinal barrier and investigate cultural, interpersonal, and intrapsychic factors related to the stare.

Nancy Eiesland, in *The Disabled God*, seeks to construct a liberatory theology of disability through the transformation of Christian symbols.[70] She sets out criteria for a liberatory theology of disability—it includes both the contingencies and the ordinariness of a life with dis/ability. A liberatory theology of disability demands new or reformed symbols, symbols with "two-way access," that is, "[p]ersons with disabilities must gain access to the social-symbolic life of the church, and the church must gain access to the social-symbolic lives of people with disabilities."[71] It is also crucial that the symbol be credible to both persons with dis/abilities and nondisabled people. In her theological construction, the transformed symbol is the embodied and resurrected Christ, the disabled God who, with crushed hands and feet, makes his way along the roadsides and near the sea and eats and talks with friends.

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[70] Nancy L. Eiesland, *The Disabled God: Toward a Liberatory Theology of Disability* (Nashville: Abingdon Press, 1994).
[71] Eiesland, 20.

Reconstructed symbols that have meaning to people with dis/abilities and nondisabled folks alike, and that articulate a theology based on justice, must translate into practices in which all may fully participate. Eiesland has experienced exclusion in the practices of the church. The Eucharist is a central Christian practice in which she cannot fully participate. In her faith tradition, the usual manner of receiving the elements, the fruit of the reenactment of the body of the disabled God broken for all humankind, is to come forward and kneel at the communion rail. Her body of "metal and plastic, bone and flesh" is unable to assume the prescribed bodily position for receiving the elements.[72] Accommodations are made, of course, for her to commune. However, what is a corporate practice for most everyone else in the congregation is a solitary one for her.[73]

She suggests that the decision-makers are asking the wrong question. Rather than wondering how to accommodate her body, the question that needs answering is: "How do we alter the bodily practice of the Eucharist in order that this individual and others with dis/abilities would have full access to the ordinary practices of the church?"[74] Excluding people with "nonconventional" bodies from ordinary practices "dishonors the disabled God."[75]

Like Eiesland, I am interested in theological constructions that are liberating to people with dis/abilities. I agree with her that there are parts of the Christian tradition that have been ignored or unrecognized or that, with reconstructed or reemphasized interpretations, can contribute to more inclusive and just relationships for people with dis/abilities in church and the wider society. She identifies herself, as do I, with the

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[72] Eiesland, 22.
[73] Eiesland, 112.
[74] Eiesland, 112.
[75] Eiesland, 113.

social political model of dis/ability (though she refers to it by another name, the "minority model of disability"). We both utilize personal narratives—she begins with a biographical study of Diane De Vries and the writings of Nancy Mairs. I begin with the personal narratives of Joanne, Camille, Rebecca, Liz, and Edie. Like Eiesland, I find many church traditions and practices to be biased against, condescending towards, and excluding of people with dis/abilities.

Though our interests overlap, my focus is different than hers. Eiesland focuses on the development of an image of the Divine, Christ as the Disabled God. In contrast, I emphasize a particular gesture, the stare, which both symbolizes and (re)creates unjust relationships between people with dis/abilities and nondisabled persons. One goal of this emphasis is to learn from women with dis/abilities effective means of challenging discriminatory practices while living as fully as possible in the midst of unwelcoming environments.

In *A Healing Homiletic: Preaching and Disability*, homiletics professor Kathy Black offers a view of the Gospel healing narratives that challenges the ways these texts have been interpreted and preached in the past and that approaches the texts with the perspectives of persons with dis/abilities in mind.[76] Traditional ways of interpreting and preaching the healing texts have contributed to theological and social barriers toward people with dis/abilities.

The first part of this book introduces background information on theological perspectives of dis/ability and the hermeneutic task of moving between the first century C.E. and today. Chapter 1 challenges traditional theologies of dis/ability, especially

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[76] Kathy Black, *A Healing Homiletic: Preaching and Disability* (Nashville: Abingdon Press, 1996).

divine agency in dis/ability. Black argues that the place to look for the activity of God is not in causes of dis/ability but in caring relationships and welcoming communities. Chapter 2 discusses the leap between the centuries—the first century C.E. when the Gospels were written and today as the texts are preached. Part of the hermeneutic task is acknowledging the gap between the cosmology of the ancient world and the worldview of the postmodern era, especially in terms of dis/ability, sickness, health, and healing.

In part two, Black turns to healing texts about specific dis/abilities, e.g., blindness, deafness, and so forth. The uniqueness of her approach to these texts is that she looks at them from the perspective of people with dis/abilities. She presents interpretations that allow the reader or listener to recognize people with dis/abilities as actors in their own lives and stories rather than objects or potential object lessons.

A Healing Homiletic makes an important contribution to the conversation about dis/ability and Christian faith and practice. It offers an alternative view to centuries of harmful textual interpretations and preaching. It invites the church to transform its relationship with people with dis/abilities. It evaluates theological assumptions about dis/ability and the activity of God. However, because it is a book about homiletics, not pastoral care and counseling, the primary texts are Gospel passages, while mine are women with dis/abilities. Black's focus is on the ministry of preaching while mine is on ministries of care.

In *Copious Hosting: A Theology of Access for People With Disabilities*, Jennie Weiss Block proposes a theology of access and a spirituality of friendship based on a dialog between dis/ability activism and Christian tradition.[77] In the first section of the

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[77] Jennie Weiss Block, *Copious Hosting: A Theology of Access for People With Disabilities* (New York: Continuum, 2002).

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book, Block introduces some of the major issues of and developments in the dis/ability rights movement. The second section calls for new interpretations of Christian theologies and doctrines related to anthropology, embodiment, spirituality, and justice from a dis/ability perspective. She also critiques Christian texts and worship in conversation with dis/ability issues. In the final section, Block presents her theology of access, arguing for inclusive Christian communities. She, then, goes on to state that accessibility is not enough. Genuine friendship between nondisabled people and people with dis/abilities is needed.

Both Block and I value and work toward the full incorporation of and participation by people with dis/abilities in communities of faith. However, we approach this goal from different vantages points. Block is steeped in Roman Catholic traditions whereas I am informed mainly by Protestant traditions. The lens through which she views dis/ability and the church is primarily the field of classical theology. I approach the topic from a pastoral theological perspective. Block occasionally utilizes her experience as an ally and advocate for people with dis/abilities, though she emphasizes the historical and philosophical contexts of dis/ability. I focus on the experience of women with dis/abilities within a social political context. Our works are compatible but distinctly different.

In *Human Disability and the Service of God*, edited by Nancy L. Eiesland and Don E. Saliers, scholars from representative disciplines in theological education reflect on the "full participation of people with disabilities in the life of the Christian church."[78] Each essay considers religious practices with dis/ability as the lens that focuses the

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[78] Nancy L. Eiesland and Don E. Saliers, "Preface," in *Human Disability and the Service of God*, ed. Nancy L. Eiesland and Don E. Saliers (Nashville: Abingdon Press, 1998), 16.

inquiry. The disciplines of the authors include biblical studies, liturgics, theology, sociology of religion, and Christian education. Pastoral care and counseling is not represented. However, if one includes seeking justice and well-being for persons with dis/abilities as a goal of pastoral care, then this book is kin to the field of pastoral care.

One essay hold particular interest for me. In "Toward a Spirituality of Inclusiveness," Don E. Saliers states that inclusivity matures into belonging.[79] With this thought Saliers put into words a thought I was struggling to articulate. It was clear to me that inclusivity, though certainly a commendable action, stopped short of the goal of full participation by people with dis/abilities. The church that opens its doors to welcome and include others still makes "us" and "them" distinctions. "We" welcome "them." The church as a place where all belong has no need for such differentiations. The concept of belonging as the maturation of inclusivity helped me name a practice of communities of faith that goes beyond including others.

Paula Buford's essay, "Women with Acquired Disabilities: Constructing New Lives in a Strange Land," describes the experience of women whose lives have undergone a significant change due to chronic, incurable, and unpredictable dis/abilities that began in adulthood.[80] This essay does not lend itself to easy categorization. Buford, a pastoral counselor and artist, finds both the unpredictable body and certain cultural systems problematic. I place her work within the social political model for two reasons. First, she writes from first-hand knowledge of living with an acquired dis/ability and

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[79] Don E. Saliers, "Toward a Spirituality of Inclusiveness," in *Human Disability and the Service of God*, ed. Nancy L. Eiesland and Don E. Saliers (Nashville: Abingdon Press, 1998), 29.

[80] Paula Buford, "Women with Acquired Disabilities: Constructing New Lives in a Strange Land," in *In Her Own Time: Women and Developmental Issues in Pastoral Care*, ed. Jeanne Stevenson-Moessner (Minneapolis: Fortress Press, 2000), 333-50.

gives voice to the experiences of women she has interviewed. Second, she focuses on the task of constructing a life with a new, different, uninvited, and unpredictable body. The task these women face in living with an acquired dis/ability is building a new life not based on the world's expectations but on careful attentiveness to their bodies. "A woman who lives in the strange land of disability rebuilds her life by listening to that still small voice inside of her."[81] These reconstructed lives are often counter-cultural. They do not follow paths that a fast-paced culture valuing self-sufficiency typically applauds. The abilities and needs of their bodies take precedence over society's expectations, even over their own personal expectations and wishes.

In addition to pointing out the difficulties of living with unpredictable bodies, Buford underscores the difficulties cultural systems present for some of the women she interviewed. The essay begins with the words of Kathleen (a pseudonym), "Beyond a doubt, the church has been the most harmful [place for me to be as a disabled person]."[82] Some of Buford's interviewees also name the family as a source of problems for women with acquired dis/abilities. Marriages are stressed and sometimes end. Parents fail to see a grown daughter as an adult. Even societal systems originally designed for the benefit of persons with dis/abilities are damaging. For example, the medical establishment misdiagnoses symptoms or minimizes the importance of them in the women's lives. The Social Security disability system assumes the claims of some of the women are fraudulent.[83] Court battles with Social Security are struggles not only to save their dignity and honor but also to have the financial means to avoid homelessness.

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[81] Buford, 346.
[82] Buford, 333.
[83] Buford, 333.

Buford's work makes a number of contributions to the conversation about dis/ability and the church. It is, as far as I know, a first in pastoral theology, care, and counseling literature in its focus on women and dis/ability. It begins with, and primarily focuses on, the experiences of living with an acquired dis/ability, from the perspective of one who finds herself in that position. Buford presents her list of opportunities for "ministry by, with, and for persons with disabilities" only after she has described both commonalities and differences in the experiences of the women she interviewed.[84] Her suggestions for ministry *grow out of* the experience of living with a dis/ability. Her main concern is learning from women with dis/abilities in order to respond appropriately. Helpful pastoral care is not generic; it is a response to the experiences and needs of particular persons. Furthermore, the role of women with dis/abilities is not only as receivers of care. They may work with others to set up systems of care. They may provide care to others.

Similarities exist between her work and mine. Both of us begin with the stories of women with dis/abilities. We both write from within the experience of dis/ability, letting our own perspectives inform our studies while striving not to dominate the views or stories of others. We are both pastoral theologians and pastoral counselors and, thus, are informed by theological reflection, cultural as well as individual experience, and the practice of ministry. The primary difference in our work is that Buford focuses on women with acquired, less visible or invisible dis/abilities whereas my investigation centers on women with visible dis/abilities. My point of entry into the topic of women

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[84] Buford, 347.

with dis/abilities is the stare, a gesture that would not be of major significance to a person with a less visible dis/ability.

Social Location

My interest in the intersection of women, dis/ability, the stare, and pastoral theology and practice grows out of my life experience as a clergywoman with a dis/ability who has been involved with pastoral theology and ministries of care in parish, hospital, and counseling settings. Experiences of dis/ability and with the church have influenced who I am and the ways I see the world. A few are relevant to the topic of this work, because they illustrate the difference in perspective existing between one who lives with a dis/ability and others who do not.

I learned early in elementary school that I was "easy to spot even in a crowd" and that others assigned "corporeal deviance" to me. It often happened during recess. I would be out on the playground running around with friends when, suddenly, a child I did not know would appear in front of me, interrupting my fun, and say, with a disdainful expression on his (usually it was a boy) face, "What's *wrong* with you anyway? You walk *funny!*" Though this occurred often enough, each time I was stunned. I was playing with friends, blissfully oblivious to the world around me, while others were scrutinizing my body and its movements.

That the appearance of my body did not fit the larger world's assumptions about bodies was confirmed by adults, as well. When I was in the second grade, my mother signed me up to attend a dance class, because a friend's mother had enrolled my friend in the same class. After the third or fourth class, the teachers asked my mother not to bring me back. Of course, I knew I was not picking things up as quickly as the other children,

but I was enjoying myself and proud of myself when I did finally perform the expected motion to my satisfaction. Thus, I learned that some people thought I was peculiar and that this peculiarity led to exclusion and that my satisfaction with my body and its movements was not very significant. It was several more years before I could see myself with society's eyes and understand how others came to make such conclusions, whether or not those conclusions made sense to me.

Seeing from the outside is quite different from living within a body. As a child I was actually rather comfortable within my body, which felt quite normal and natural to me. This is not to say that my physicality did not, and does not, cause me challenges. The effects of aging, in particular, have added a dimension of unease and awareness that were not present in childhood and during my young adult years. However, it is chiefly through the reactions or responses of others that I became aware that the things in my environment that physically challenge me are easy for most other people.

Thus far, I have been talking only about the parts of my body that are visible to others. I also have an invisible dis/ability. Over the years, it is the invisible structural "anomaly," detectable primarily by x-rays, that has caused me the greater physical problems, including pain that is at times excruciating, surgeries, and periods of recovery. It is all the more remarkable and ironic that the visible dis/ability is of concern to society, because it is the invisible dis/ability that causes the most disruption for my life, that is, from a physical, not social, standpoint.

Though I was quite young when I learned that my body form and motion did not, and does not, seem natural and normal to many people, even now it often comes as a surprise to me when this fact confronts me. Therefore, I am not an unbiased reporter of

social phenomenon. This work is certainly informed by my experiences of discovering society's rules about and expectations for bodies and the consequences of transgressing those norms.

Nonetheless, I have also learned a great deal about the variety of experiences of women with dis/abilities as I reviewed the literature and spoke with other women. My perspectives have broadened from exposure to a range of women's experiences with dis/ability and with religion and religious people. I have learned that women with dis/abilities have diverse experiences of and responses to dis/ability and a variety of perspectives on interactions with communities or persons of faith. This multiplicity of experience is reflected in this work.

As a person with ordained status in a Christian denomination, I am confronted with Christianity's conflicting and contradictory relationship with issues of embodiment and dis/ability. Furthermore, Christianity's difficult relationship with questions of body, dis/ability, and persons with dis/abilities has influenced and reinforced popular cultural views in the United States, the country of my birth and citizenship. The Christian church, like any large system, resists change. It is often difficult for humans to imagine a reality different than the status quo. A few years ago at a spiritual retreat, I encountered a situation that dramatically brought home to me the restricted and compartmentalized perceptions of otherwise good people regarding dis/ability and the practices of nondisabled people.

It was a week-long retreat that focused on an examination of Christian views of the body. The leader of the retreat was a minister who has a progressive and debilitating disease. Several persons in attendance at this retreat had dis/abilities, either permanent or

temporary (such as a broken leg). One day, after three previous sessions about views of the body in Christian history, the leader told his own story of his struggle with his illness and dis/ability and the systematic exclusion of people with dis/abilities in both church and society. The hush of those gathered seemed to reveal compassion for his experience and pain at the injustices he faced.

His presentation was followed by a session of "body movement." Unfortunately, the leader of this part of the program had designed an exercise, a "blessing," that required bodies that move about easily, that is, nondisabled bodies. As she began to lead participants through this exercise, those present who had dis/abilities started to line up on a row of chairs on the periphery of the room, outside the area where the "blessing" ceremony was being performed. The body movement exercise was reenacting the same exclusionary practices the presenter had spoken of only minutes before. I would like to say that, because of the earlier presentation, the leader and the participants immediately recognized what was happening and made appropriate alterations so that all bodies could be included. But that never occurred. I watched in astonishment and horror for a while and then left, unwilling to be "blessed" and refusing to be excluded.

Later, I spoke to members of the leadership team. Each one expressed concern that I was distressed, but few could even begin to comprehend the social implications of what was acted out. Few were open to considering that the problem resided in the communal assumptions and actions and not in the one, me, who pointed it out. I was extremely discouraged by this incident. My frustration at and realization of the disconnection between participants' sympathy for and criticism of the exclusion

experienced by the speaker and the exclusionary practices enacted is, in part, the impetus for this work.

I have defined the terms related to dis/ability; described the major frameworks used to understand dis/ability; reviewed the scholarly literature relevant to dis/ability and Christian theologies and practice; and identified my perspective toward the topic. In the following chapter, utilizing the tools of nuanced terminology, multiple models of dis/ability, and pastoral theology, care, and counseling literature, we listen to personal narratives, including stories of the stare, told by the women I interviewed. Before I give summaries of the interviews, I discuss one additional interpretive tool, the notions of dominant and alternative knowledges. The stories of marginalized persons, such as women with visible physical dis/abilities, are a treasure of knowledge alternative to dominant paradigms.

CHAPTER 3

WOMEN'S LIVES, DIS/ABILITY, AND THE STARE

The narratives of women with dis/abilities are the heart of this chapter and this

dissertation. In the first section, "The Role of Narrative in Human Life," I briefly explain

the concepts of dominant and alternative narratives in human lives and culture. The lives

of women with dis/abilities reveal alternative narratives that challenge modern culture's

assumptions about dis/ability. The second section, "Women's Narratives," introduces

each of the women I interviewed by giving a synopsis of the interview. My

conversations with the women generally began with their experiences of being the objects

of stares and the impact of that on their lives. Other aspects of their lives—such as

childhood experiences of dis/ability, encounters with medical professionals, the contrast

in their lives before and after dis/ability occurred, and interactions with religious

people—were also part of their narratives. Though this dissertation centers on the stare,

the narratives I recount include more of life than the stare. Experiences of the stare do

not exist in isolation, rather they are embedded in the narratives of particular individuals'

lives. Unfortunately, modern concepts of the body fail to embrace comfortably lives and

bodies with dis/abilities. Therefore, the final section, "Rethinking Embodiment,"

explores the necessity of revisiting theologies and practices of care in order to create

environments where all persons belong.

The Role of Narratives in Human Life

Human lives are embodied narratives. Our bodies carry stories we cannot even

recall. Medical records hold stories of our bodies written by others. Had we a hand in

the writing, those records might tell very different tales. Our beliefs and our cultures'

beliefs contain narratives written on and in our whole self—body, psyche-soul, mind, emotions. Christianity is based on the story of an embodied human who, Christians argue, revealed the likeness and intention of the Divine. Our personal, cultural, and religious narratives are written in very complex ways. The story itself, the ways narratives are constructed, the writing in or leaving out of certain episodes in our lives, and the choices we and others make in detailing the history of individual and corporate lives are crucial elements in Christian faith, in pastoral theology, and in ministries of care.

Pastoral ministries of care have to do with telling and listening to stories. They may entail creating together new stories or new understandings of old stories. They involve asking how our personal and communal stories relate to the narrative of the Divine at work in the history of the world. Stories are rarely static—with each new telling, a story becomes a different tale. It may alter or confirm who we are, what our lives are about, and where we find meaning in the scheme of things.

There is story in the stare. The stare itself is a story of beliefs about human value and dignity, about the sacred and the profane. The story in the stare tells us that some persons, because of their physical way of being in the world, are believed to have a greater claim to full humanity, truth, and power, and that other persons, due to their physicality, are believed to be diminished or restricted in their claim to the fullness of humanity and abundant living.

The theories of Michael White regarding the therapeutic uses of narrative are instructive in understanding the stories persons live out.[1] White draws on French philosopher Michel Foucault's work on "unitary knowledges" and "subjugated knowledges." Unitary knowledges or "normalizing truths" refer "to those knowledges that make unitary and global truth claims."[2] These "truths" shape the lives of persons according to pervasive societal norms. The dominant truths or narratives underlying the stare shape the lives of both nondisabled people and people with dis/abilities. No one escapes their influence.

But there are other kinds of knowledges as well. The storied experiences that contradict unitary knowledges Foucault calls "subjugated knowledges." He identifies two types of subjugated knowledges. One is termed "erudite" and is comprised of knowledge that is deleted from the dominant narrative through the revision of history; the second, known by several names—"local popular," "indigenous," and "regional knowledges," includes the knowledges of marginalized peoples.[3] To the extent that people with dis/abilities are marginalized, their storied experiences, which contradict the unitary or dominant truths and narratives, are a form of this second type of subjugated knowledges. They make up the alternative stories which challenge the truth claims of the dominant narratives.

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[1] See Michael White and David Epston, *Narrative Means to Therapeutic Ends* (New York: W.W. Norton, 1990), esp. chap. 1, written by Michael White, which outlines his theories and their connections to the work of Michel Foucault, referencing *Discipline and Punishment: The Birth of the Prison* (Middlesex: Peregrine Books, 1979); *Power/Knowledge: Selected Interviews and Other Writings* (New York: Pantheon Books, 1980); and *The History of Sexuality* (Great Britain: Peregrine Books, 1984).

[2] White and Epston, 20.

[3] White and Epston, 25-26.

Each person's life includes dominant narratives that may serve her well and ones that do not. Marginalized people also have storied experiences that counter the truth claims of the dominant narratives. The alternative narratives of marginalized people are not one but many. Some narratives are variations on the same theme, while others form a cacophonous sound with disharmonious melodies. My focus throughout this dissertation is on the narratives of the dominant culture in the United States of America which find women with dis/abilities wanting, especially as communicated through the devaluing stare, *and* on the alternative narratives that challenge the dominant message. I am especially interested in alternative narratives women with dis/abilities create that contribute to their well-being.[4]

Women's Narratives[5]

I met individually with five women who spoke with me about their experience as persons with dis/abilities and told me stories of their lives, including stories about being the object of stares. They relayed, commented on, interpreted, and analyzed some of the events that make up their personal narratives. In a single interview, each could share with me only a slice of her life. Nonetheless, this slice is crucial to pastoral theologians, and persons involved in ministries of care, who view human beings and their experiences as the primary texts for the work we do.

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[4] There also may be dominant narratives that are helpful, though limiting, and alternative narratives that are destructive to women with dis/abilities (theory does not place a value on unitary knowledges or on subjugated knowledges). For example, to obtain government benefits or charity, one may have to emphasize one's neediness and compliance and minimize, if not deny, one's strengths. This may be essential to survival but detrimental to psychospiritual well being.

[5] Some non-essential data about the women has been changed for reasons of confidentiality.

Joanne

Joanne is an African-American woman in her fifties who, as noted in Chapter 1, identifies her dis/ability as cerebral palsy. She lives alone in Phoenix, Arizona and is an active volunteer in her congregation and denomination. The church has played an important role in her life since she was a child. It was a place of refuge from a family life with a history of alcoholism and violence. Joanne recalls a friend of the family once remarking, " 'I don't know how you guys are alive.' "[6] In order to survive, she sought sanctuary in a nearby church when "my mom was on a rampage." The church was the place where she felt happy and secure. She describes her family as "dysfunctional" and her childhood experience as including neglect and abuse.

When I asked Joanne to tell me about the times she had been the object of stares, she recalled a number of incidents when people had looked at or listened to her and formed false and/or negative judgements about her. The stare, for her, is a symbol referring to a wide range of demeaning experiences in her life that focused attention on her bodily particularities, labeled dis/ability by church and society.

Her dis/ability, which was present at birth, has been a source of shame for members of her family. She recalled, as a grade school child, coming across her little brother crying in the yard of his nursery school. When she approached, he sobbed, "They told me you were *crippled*. Tell them you're not *crippled*. You're not *crippled*, are you?" This happened over four decades ago, but she remembers and still feels his hurt and pain at someone's comments about her. Her brother, a preschooler, was too young to

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[6] The words, phrases, and sentences spoken by the women I interviewed are indicated by quotation marks.

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know what the word "crippled" meant but old enough to understand that others thought it was something one would not want in one's family.

Joanne "*hate[s]* that word [crippled]" and celebrates its replacement by other words. As a child, she had contact with an organization that at the time was called "Crippled Children's Society" but has changed its name to "Abilities First." Joanne's response to the renaming was, "It's about time!" Though change has occurred in some areas of her life, the shame her family felt about her continues. She is excluded from family events if persons outside the family will be present.

Joanne left home at the age of eighteen, but finding a place to live had its own difficulties. A social worker helped her search for housing. They tried to get her a room in the YWCA. Joanne and the social worker went together to the interview. The YWCA denied her request because of her dis/ability—they worried that "something might happen," because their facilities included, among other things, a pool. For Joanne, the rejection was "devastating." She eventually found living quarters, but not until the social worker suggested a change in their strategy. Rather than the two of them going together, Joanne waited in the car while the social worker alone spoke with the director of a residence for international women studying or working in the city. After the director agreed to accept Joanne, the social worker invited her inside. Joanne giggled as she told the story of this tactic on the part of her social worker. Her giggles reveal delight in the cleverness of the social worker and in her own ability to create an alternative narrative that included living on her own.

It was during the three years Joanne lived there that she came to realize "all the things I had to overcome" compared to nondisabled people. Prior to this time, she had

feared and avoided nondisabled people. Her classmates in the "regular" school, which she attended in the early elementary grades, had been cruel to her. She remembers being beaten up and thrown down stairs. When she was transferred to a school for children with dis/abilities, Joanne was surprised by the acceptance and friendliness shown her by the other children.

Once she was on her own and back in an environment populated primarily by nondisabled people, she became aware of the obstacles she faced, that others did not. Persons in authority positions made decisions based on her physical features. She had contacted the state rehabilitation agency following high school in the hopes they would help her prepare for a career in teaching. They concluded that, due to her physical particularities ("because of my speech, because of my hands"), they were not willing to pay for her to get a college education and sent her to Goodwill Industries instead.[7] That was not what Joanne wanted to do; she wanted to go into early childhood education.

Refusing to accept their opinion of her abilities, she enrolled in a community college. She ran into difficulties there, too. Although some of the teachers were supportive of Joanne's goals, others were not or were not willing to make the accommodations necessary for Joanne to meet those goals. For example, as the physical act of writing is an effort for her, she wanted to bring an audio recorder to tape the lectures. Some of the teachers would not allow that.

Another teacher believed that, if Joanne were allowed to teach, the children's needs would take second place to Joanne's needs. This teacher was responsible for

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[7] Goodwill Industries is an organization whose expressed purpose is to train people with dis/abilities so that they may become part of the nation's workforce. However, sometimes the work is menial and the pay low.

assigning placements for student teaching. She refused to assign Joanne to a school. Joanne found her own site. The same teacher refused to come to observe Joanne at work.

Even teachers who were supportive of Joanne found it difficult to make allowances for her needs. Joanne recalled one testing incident. As she needs extra time to write, the other students finished the test before she did. When Joanne was the only student remaining, the teacher picked up Joanne's paper, saying "I know you know [the material]." Though pleased with her grade on the exam, Joanne said she felt cheated. She had studied hard and wanted a chance to demonstrate what she had learned. Joanne describes the problem as the "impatience" of nondisabled people, both in the classroom and in a world designed for the nondisabled.

Church is largely a positive force in Joanne's life, though it has its painful elements as well. She has a strong faith and attributes all good things that come her way to the activity of God. She has good relationships with the clergy and lay staff of her church. She serves in leadership roles in middle judicatory bodies of her denomination. This recognition by others of her abilities and contributions confirms Joanne's sense of worth. Being sought out for leadership roles "make me feel better about myself." It can be difficult to hold onto a positive sense of self when others deny or fail to acknowledge one's gifts and potential. Fortunately, the church is sometimes able to affirm her gifts, such as the time she was invited to read her poetry at the ordination and installation of a prominent church official. She describes the church as her family.

When a society's messages about a group of people, such as persons with dis/abilities, end in discrimination toward members of that group, a part of pastoral leadership involves encouraging and lifting up such alternative narratives that move all

persons toward acting out the vision of the reign and realm of God—all people belong and all people are called into fullness of life.[8]

Unfortunately, stories of acknowledgement, affirmation, and inclusion are not the only ones she tells about the church. After high school, she explored joining a religious community. Because of her interest in education, she searched for a community with a school attached. She wrote to a number of places and found one that suited her interests. She arranged a visit. Joanne was acceptable as a potential candidate until she was seen. A friend accompanied her on the long drive. When they arrived, the mother superior showed no interest in Joanne and focused her attention on the friend, trying to convince the friend to join the community. Feeling discounted because of her dis/ability, Joanne lamented, "Even in the church, I'm not good enough."

With the encouragement of her pastor, Joanne later considered a call into the ordained ministry. However, she finally decided that her dis/ability would prohibit her from comfortably carrying out the responsibilities. She was particularly concerned about difficulties she might have holding the communion chalice. Joanne is sensitive to the power of looks and the accompanying remarks. As a communicant receiving the elements, she is aware of stares and comments. One of the particularities of her body, on which she experiences others focusing, is involuntary movement (shaking) of one hand. Joanne noted that "mainly younger kids would look at me [as if to say], 'What's wrong with you?' and then their mothers would say, 'Don't stare at her.'" She changed her

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[8] Don Saliers identifies belonging as the maturation of inclusiveness. See Don Saliers, "Toward a Spirituality of Inclusiveness," in Nancy L. Eiesland and Don E. Saliers, eds, in *Human Disability and the Service of God* (Nashville: Abingdon Press, 1998), 29. Mercy Amba Oduyoye in *Daughters of Anowa* (Maryknoll, N.Y.: Orbis Books, 1995) focuses on the rooting up of obstacles to, and the cultivation of, the fullness of life as offered in the Christ-event.

communing habits to reduce the stares: she now receives the communion host by mouth rather than in her hand, though the latter is her preference.

Despite her self-consciousness at the communion rail, Joanne is eager to participate in some areas of worship leadership, for example, reading the text or making announcements. She has been excluded from these roles in her congregation. She reports being told that it would take extra time to bring the microphone down to her and hold it for her, and someone would have to make sure that others understood her. I had no such trouble on the day I interviewed her.[9] Joanne attributes the restriction of her leadership roles to an expectation of perfection. She finds it painful to experience others concluding that she is inadequate.

Pastoral caregivers, whose focus includes enhancing the well-being of persons, are often in a position to notice the negative effects of restricted social access and to challenge and engage others in challenging such practices. In addition, ministries of care can have an impact not only in the way they offer care to people with dis/abilities (this is, after all, the expected trajectory of care) but also in offering care to the community and to those whose level of comfort with dis/ability is limited.

In both visual and auditory realms, the nondisabled world makes assumptions about her that are false and hurtful. On multiple occasions, when she is having a meal out with friends, the server will ask a friend some variation of, "What does she want on her hamburger?" The interpretation Joanne makes of this is that the server assumes she has a cognitive dis/ability as well as a physical one. Joanne recalled telling her pastor of

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[9] In an unpublished manuscript, "Poetry and Pain: The Voice of One Crying Out in the Wilderness," 2000, the Reverend Judith E. Turberg, an Episcopal priest and doctoral student at Claremont School of Theology, indicates that Joanne's speech becomes less clear during times of tiredness or stress, 8.

these incidents, but he did not believe her until the day she took him out to lunch. The server asked him about Joanne's preferences. When he suggested that the server ask Joanne, the server replied, "Can she understand?" It is not uncommon for nondisabled people to assume that dis/ability encompasses the totality of the life and being of people with dis/abilities, rather than recognizing that dis/ability is just one of many characteristics a person might possess.

Another assumption Joanne meets in folks unfamiliar with her speech patterns is that she is sick or from another country. The phone rang during my interview with her. She answered it, paused, and responded, "No, this is the way I talk." Later, she explained that the caller had asked her if she had a cold. Even more bothersome to her is someone who refuses to speak with her and asks to talk with someone "who is from the country and can speak English."

She also has had to confront the assumption that she is intoxicated. Because of the violent nature of the family in which she was reared, she was, at times, instructed by her mother to phone the police for help. When she would call and ask for help because someone in the house was "drunk or on drugs, . . . they would say, 'Well, you don't sound too good yourself.'"

These were shaming experiences for her. It is a peculiar feature of shame that, even when the assumptions are false (e.g., that she is unfamiliar with the English language or that she has been drinking), humans can feel shame at being accused. Shame can also be experienced when persons are reminded that others perceive them as

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different.[10] Incidents like these tax Joanne's self-esteem. She feels "less than" others at times. Some people, including friends, will accentuate the distinctiveness of her appearance by referring to her as "one of a kind." She notes mixed feelings about such descriptions. On the one hand, she likes being thought of as unique. On the other hand, it also can hurt, because her desire to belong, even to blend in, is strong. Not fitting in can be very lonely.

Joanne has mixed feelings about herself, too. Her emotional pain from loneliness and isolation, as well as her physical pain, can be very hard to bear. She sometimes wonders why she is alive and wishes she were not. She feels the sting of shame when others point out her dis/ability. Stares, physical pain, and occasionally needing help remind her that she has a dis/ability. At other times, while engaged in other activities such as conversing with friends, she reports that she does not feel disabled at all. She can also readily name the multiple strengths she possesses. Though society frequently sees only the disability, few people with dis/abilities would say that the disability encapsulates who they are. Joanne sees herself as a "complicated person," one who defies easy description and does "not really fit into one category." She does not get angry about many things, but she does get angry when people "just put you in a category without even seeing the person behind the dis/ability."

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[10] Gershen Kaufman, *Shame: The Power of Caring*, 2nd ed. (Cambridge, Mass.: Schenkman Pub., 1985),8, identifies shame as a response to feelings of exposure, especially as an inferior being. "To feel shame is to feel *seen* [original emphasis] in a painfully diminished sense. The self feels exposed both to itself and to anyone else present. It is this sudden, unexpected feeling of exposure and accompanying self-consciousness that characterize the essential nature of the affect of shame. Contained in the experience of shame is the piercing awareness of ourselves as fundamentally deficient in some vital way as a human being."

Joanne believes that her purpose in life is to be a light to the world by showing the face of Christ to others. She does this in diverse ways. She says she likes to surprise people, for example, by being a courteous driver. "I just like doing those kinds of things—changing people's images of a black person and a handicapped person." She also sees herself as having the ability to be sensitive to others and to listen. She believes that gifts coming from her experience as a woman with a dis/ability are part of God's purpose for her, though she knows that some folks do not agree. "Sometimes I feel like the suffering I go through, God puts me through to be able to identify with another person's suffering. Some people say it's not so, but [I'm] just trying to make some sense out of the whole thing."

Camille

Camille is a single, European American woman in her forties. She resides near Seattle, Washington and earns her living as an artist. She shows her work at galleries, flea markets, and art festivals. Camille is the only woman I interviewed who does not use a wheelchair. The medical classification for her dis/ability is "dystonia." More casually, she speaks about her "neck spasms," which result in involuntary head movements. She explained that, though the term "dystonia" includes a lot of different symptoms, it principally involves "uncontrollable movements."

Camille has lived with this condition since early adulthood. There was a period of time, following various and extensive treatments, when her condition improved in a manner that was noticeable to others. However, after a recent injury, her condition has worsened. Her symptoms have expanded to include spasms in her right (and dominant) hand, arm, and shoulder, affecting her handwriting and her work as an artist.

Camille seeks alternative methods for doing everyday activities. For example, if she has trouble writing, she finds pressing down harder on the pen helps. When the spasms get really bad, she steadies one hand with the other.

Dis/ability complicates Camille's art—in the actual performing of the tasks, for which she primarily uses her right hand, and in her interactions with the buying public—and her life. Because her dis/ability has varied—periods of time when her neck spasms were more agitated and other times when they were calmer—she has dealt with the public in both circumstances. As she reflected upon her experience under public scrutiny and the different reactions she received based on whether her dis/ability was more obvious or less, she concludes that "people are put off by the visual things they don't understand." Her view on the looks and comments she gets is that "most people don't want to ask questions, and they don't want to stare." Nonetheless, "there's this awkwardness...some people go so far [as to not] even look at you at all. They'll talk away from you." She suspects that the dis/ability has affected the extent of her success as an artist, but she thinks that she is relatively successful anyway.

Camille believes that her personal, as well as her business relationships, have been affected by her dis/ability. She speculates that, if her dis/ability had never developed, she would be happily married and have children. She states this without regret. She is satisfied with her life as it is. She enjoys her work and affirms her giftedness: "I think I'm really good at what I do."

Dis/ability complicates matters but does not stop her. In retelling the story of her early adulthood when the neck spasms began, she recalls that it was shortly afterwards that "I first started my business and...all of a sudden here I am in the public eye...and

self-conscious about my neck. But, at the same time, I've always just done things anyway. Even in the face of adversity, whatever people said or thought, I just went ahead and did my thing and struggled through whatever people said or did. I still do that."

Camille resents strangers calling attention to her body. She considers such actions an intrusion into her personal space, whether that comes in the form of unnecessary concern for her or mocking of her. She told three stories of encounters with the stare, all of which took place at public art fairs shortly before our interview. In the first episode, a woman from a nearby booth rushes over to Camille and says excitedly, "I was just telling my husband, 'I think that girl's having a seizure.' Are you having a seizure?" Camille assured the woman she was not and thanked her for her concern. However, Camille was "really uncomfortable" because her "personal behavior" was brought "up for discussion" by others.

Later, a woman saw Camille leaving for the day with all her wares loaded on her back. Carrying all her goods results in extra strain on Camille's body, but she was "trying to hold myself together and moving around a lot more [than usual]." The woman came up to her, "stopped dead in her tracks," and started laughing at Camille, saying, "What are you doing?" Camille interprets the woman's response as the woman assuming that Camille is "doing this on purpose."

Camille is angry when people make fun of her, even if they do not "get it," that is, even if they do not understand that Camille's movements are involuntary and cannot be controlled. At times like this, she wishes she had some pointed responses and laments that she rarely thinks of such comments in the moment. "Later on, I think of things to say [such as] 'You have absolutely no idea how insensitive and shallow you are being.'"

This was not the first time that someone has thought that her head movements were intentional. "I've had people say, 'Why do you do that?'" Her typical response is, "I really don't want to; it's an automatic thing that just happens." She reports that the questioner often continues, "Well, why?" Some things defy explanation. Camille experiences such questions as showing the "insensitivity of people." Unfortunately, it is not uncommon for persons with dis/abilities to be confronted by non-disabled people requesting explanations and assuming they have a right to them.

In the third episode, Camille was setting up her booth when a man in a neighboring booth began to insist, in a manner that felt "ugly" and "nasty" to her, that she move her car, which was parked in front of her booth—immediately. When she did not respond quickly enough, the neighbor's "friend [said], 'Look at her.' And he starts doing this kind of mumbo jumbo talk and jerking his head around. And I just said, in this big loud voice, 'Hey!' . . . I walked over and put my arm around him and I [said], 'Do you often make fun of other people's handicaps?' And he went, 'Uh, no.'" The man seems to have thought of Camille's dis/ability as a quirky habit that he could use to needle her. Camille's impression was that this was a "mean-spirited" man who unconsciously but "instinctively [knew] what buttons to push." This time, Camille was pleased with her response. She acted in the moment, she named his action as making fun of a dis/ability, and she challenged this activity. In each of these three episodes, someone is bringing into the public sphere her bodily particularities, which she holds as a private and personal matter. In each case, the person has misinterpreted Camille's circumstance and responded to her as if their perceptions were accurate.

Camille's discomfort with people making her body, a private domain, a realm for public discussion might cause persons engaged in pastoral practice to examine the assumptions each of us has. We can explore what human characteristics we take for granted as "normal" or "natural" and about what we are curious and ask questions. Persons in pastoral roles have the opportunity for an emotional and spiritual intimacy afforded to few other persons. Yet, we can be more alert regarding when and how we decide to delve into matters that may be considered personal. Pastoral theology, care, and counseling, centered in a holistic view of persons, offers alternative practices to the stare, the insensitive questions, or avoidance, which may arise from such interactions.

One alternative practice would involve resisting the inclination to pigeonhole someone based on a single characteristic and, instead, recognize that there is more to a person than any one feature or group of features, that everybody has multiple physical traits. Persons offering pastoral care and counseling have the opportunity and responsibility to communicate this holistic view of persons to individuals, both nondisabled people and people with dis/abilities, and to communities.

Camille appreciates persons who look "beyond" her dis/ability, that is, they recognize that there is more to her than a dis/ability, confirming her belief that her particularities are "no big deal." "No big deal" does not mean no difficulties. She acknowledges that her eyes do not focus well with her head in motion, that the spasms affect the use of her arm, and that pain accompanies the spasms. She would prefer not to have the dis/ability and, in years past, has undergone multiple treatments to lessen the spasms. When her symptoms abated for a time, Camille had mixed feelings. She was glad to be feeling better. She valued the lack of unwanted attention. At the same time,

she went through a period of mourning for the self that no longer was. She had had a body that worked in a particular way all of her adult life. Its habits and sensations were familiar to her and, though satisfied with the desired changes, still a sense of sadness accompanied them. Camille had become comfortable in her body, even a body that made others uncomfortable and caused her some distress.

Her belief system supports the notion that things happen to people because they have something to learn. She engages in self-examination to discover what it is that she has to learn from her experience with dis/ability. The recent injury, which exacerbated her symptoms, further convinced her that she had failed to learn whatever it was that she was supposed to learn. The corollary to this belief is that, if she learned this lesson, the dis/ability would go away. Yet, at the same time that she concludes she "must have done something in my life to deserve this," she can reject the idea that she is responsible for her dis/ability, stating that it is something that "just happens." She understands her dilemma and can laugh at herself, saying, "It's a deeply psychological thing."

Camille is able to hold fast to her sense of herself as whole, as fully human, as not defined solely by her dis/ability. Part of her physicality has to do with a physical dis/ability. She admits, "I'm not exactly thrilled about having this." Though it has an impact on all of her, it is part of the whole of who she is, not the entirety of her being. Though others may focus on her dis/ability, she does not. Though she can become self-conscious about herself, especially when she perceives others to be staring at her, she prefers to just go on with her life and her business. "I've always just done things anyway."

Bodies do not have to conform to society's ideals for humans to inhabit them well. All any of us, with or without dis/abilities, can do is lead our lives with the bodies we have. We can fully live with the limits and potentials that exist at any given time. Ministries of care can honor both physical limitations and possibilities. We can reevaluate our understanding of humanity in such a way that that takes into account diverse experience, seeing the richness and complexity of human being and human doing.

Rebecca

Rebecca, an European American woman in her late twenties, lives in Berkeley, California with her partner, Anne. She is a graduate student working on a doctorate in English. She combines her interest in literature with dis/ability studies. Before she became disabled, artistic endeavors were central to her life. Painting continues to be an avocation, though work in some other media is no longer an option. Rebecca grew up in a church-going family and, as a teen, was active in church. In early adulthood, she decided she could no longer assent to much of the theology expressed in the liturgy and by the church. She describes herself as having a "reverential view toward nature."

For Rebecca, whose legs were amputated after she was critically injured, stares are extremely common. "When I'm putting my chair together, when I'm rolling into the store, or actually getting stuff off the shelves, people are staring at me for each of those activities." She characterizes stares as a "normal part of my existence." Because eyes seem to follow her almost everywhere she goes, she pays little overt attention to most of them. "I don't think about them at the time, because I would never get anything done."

Initially, she said that she could not "actually remember where I was or who was staring at me" in the brief, everyday encounters. Then, following a moment of self-

reflection, she recanted. "Okay, that's not true—I can remember being on one particular

corner and remember that someone was staring at me or picture a person's face while

they were staring at me." She does notice the stares "on a subconscious level," but she

usually does not let them get in the way of what she is doing. There are times, though,

"when a more significant staring event happens. . . [or when] they build up. Once there's

enough of them, then, all of a sudden, I have to deal with them." Sometimes, when this

occurs, she becomes "depressed" and feels "very abnormal." On those occasions, "I

forget that I really do lead a relatively normal life." These moments are painful.

Fortunately, they do not last. Eventually, something occurs that calls her back into

engagement with life.

As Rebecca described the stares she receives, three major categories emerged.

One group she identified as representative of cultural conceptions of dis/ability. Another

group of stares she classified as having religious meaning—for the other person. She

also encounters stares that she interprets as coming from a place of curiosity. The

specific comments that people make to Rebecca lead her to connect their stares to a

particular category. When a person says something to her, she assesses whether the stare

reflects cultural or religious ideologies or a curiosity about dis/ability. Rebecca's

development of a taxonomy of stares makes clear that staring is not a covert operation.

People who stare may think they are discrete and invisible, but the receiver of the stare

normally notices, records the event, and categorizes them.

Encounters with stares that are based in cultural portrayals of people with

dis/abilities can be extremely distressful. Rebecca detailed an incident which occurred

less than a year prior to our interview.[11] A man on the street, who had been staring at her as she rolled along the sidewalk, initiated a conversation with her. After asking her whether or not she could "do" anything, he told her quite bluntly that he thought she was horrible to look at. This was a disturbing encounter for Rebecca. Gaining some sort of emotional equilibrium following that incident required a brief period of withdrawal and the recollection that the people close to her share a very different view of her than this stranger on the street. In the moment of confrontation, she felt as if "it was about me—how I am and who I am. . . . There's something wrong with me. I'm the one who's disabled. This is my problem." As time passed, she found it helpful to "give myself a 'reality check,'" to consider her goals, her life, her activities, and the people she is involved with on a daily basis. She moved to "seeing it not as my problem but as his problem." This man's conclusions about Rebecca are discordant with the reality of Rebecca's life. He lacks knowledge about dis/ability—this, she eventually decides, reveals something about *him*, not about her.

Another group of people who stare and make comments about Rebecca's dis/ability are "religious folks." Dis/ability literature typically depicts religious beliefs about dis/ability falling into a saint-sinner dichotomy, that is, the belief that dis/ability is the result of sinful activity by the disabled person or a family member or due to a saintliness that allows the individual to deal with dis/ability with grace. Although Rebecca more frequently gets assigned the "saint" label, she told one story about being on a pedestrian street in a large university town when a man told her, complete with scriptural reference, that she and her family had sinned and that was the reason she was in

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[11] This narrative is analyzed in detail in Chapter 6. Other aspects of this encounter are presented in Chapters 7 and 8.

a chair. A friend who was with her became angry with the man and told him to go away. Rebecca said she laughed when he pronounced her "evil." She described the man as "yelling and gesturing in the streets. People were staring at him. . . . Yeah, so I did laugh. . . . That's not a deep, hidden fear of mine—that I've done something wrong and that's why I'm this way. There's no part of me that believes it." She reflected that, had she been alone, had he spoken calmly, or had the incident occurred soon after her injuries when she *was* wondering why this had happened to her, perhaps the incident would have affected her. But the way the scene was played out seemed "ridiculous" to her, and she did not take it seriously.

People who see her as a symbol for saintliness make her more uncomfortable than that man did. They want to touch her—her hands, or head, or shoulders. "They think I'm so *amazing*." Strangers tell her that they see God in her, that she is proof prayers work, and that they feel God when they look at her. People have even verbally compared their own life circumstances to hers and made comments, such as—"Wow. My life is really good. I'm not going to feel sorry for myself anymore. I don't have it bad because [you've] got it bad." She notes that people who make those comments "think it's a compliment." The "amazing" attribute is echoed by folks who do not use explicitly religious language. Rebecca has formulated a couple of theories about why folks find her so amazing.

> I think it's two things—one, that I'm still here. Looking at my body, it's clear that I went through something. . . . So, I think part of it is a survival thing. The other aspect of that amazing thing is this assumption that people who are disabled are angry and depressed and can't do anything. So, I think part of [it] is: "Wow. You're not any of those three things. You don't seem angry. You don't seem depressed. And, you're out here in the world". . . . I think they don't have enough experience in their lives to know that there are a lot of people with dis/abilities who do all sorts of stuff—they just don't know about them.

Rebecca has mixed feelings about people who stare and make religiously oriented comments to her. On the one hand, she senses that they are experiencing some connection to their "higher power" (her phrase), a connection with which she is hesitant to interfere. On the other hand, it bothers her when people use their interpretation of her body and circumstances to support religious beliefs that she does not share.

Related to the religious characterizations of sinner or saint is an attempt to make meaning out of the workings of the world, to reassure oneself that life's happenings are ordered and reasonable. Sometimes Christians try to reassure themselves and others that unexpected and unwanted events are manageable by offering "pat" answers to difficult circumstances. For example, one might hear, "All things happen for good" or "God doesn't give us anymore than we can handle." A pastoral caregiver who responds with simple comments like these risks cutting short a person's journey into meaning-making. Furthermore, these statements are not necessarily true. Some events do not have good outcomes. Some people do encounter situations in which they are overwhelmed and for which they are not prepared. Sayings such as these can trivialize the gravity of a situation and the difficulties a person is experiencing. To fail to acknowledge the difficulties of a stigmatized and marginalized position in society is not caring.

The majority of the stares Rebecca gets are "quick" ones, without comment. She interprets these as curiosity, that is, people are wondering what happened to her and how she does what she does. Rebecca comes to this conclusion because of the questions children ask her, her own sense of curiosity, and the reactions of some adults. She experiences the questions and reactions of very young children as being honest and as lacking the prejudice and value judgment of adults and slightly older children. "They

don't understand why I don't have legs; I tell them; and then they don't care. They really don't care." The questions of children help her deal with the stares of adults. It seems as if the curiosity of children encourages Rebecca to see a curious child in adult stares.

She acknowledges staring at people out of curiosity. "I stare sometimes at things I don't understand. It's not that I think there [is anything] wrong. I'm just trying to figure [something] out. . . . I sometimes look or even stare at people with dis/abilities [that are] different from mine, because I'm trying to figure out what dis/ability they have. And, if their dis/ability is somewhat similar to mine . . . I'm trying to figure out how they did that—whatever it is they're doing."

Most of the time, the stares she labels "curious" are not accompanied by comments, but sometimes they are. She does not mind a question from someone who has some familiarity with dis/ability, for example, "a question like, 'My sister's in a chair, where did you get those gloves?'" At times, she senses adults staring at her, wanting to ask her a question. Though she admits she is not always right, she thinks she can see a question in people's faces—"the head turns, mouth opens [as if] 'I want to ask you something, but I'm not sure if I should.' And a lot of those people, if you look at them and give them permission with your own face . . . will go ahead and ask." She also says that sometimes they do not ask the question, as if they have changed their minds.

When no words accompany the stare, Rebecca cannot know for sure if the stare is one that carries society's negative value judgments, one with religious meanings, or one signifying curiosity. However, since she does not experience stares of curiosity as harmful, Rebecca interprets unspoken looks that way.

> By reading [a stare as curiosity], it's easier to go on with my life, because it's not someone making value judgments; it's someone who wants to understand

something different. I don't think that's necessarily bad. . . . Someone staring at me out of curiosity is [not] such an erasure of my identity or such a violation of who I am the way someone staring at me and making a value judgment is.

This method of interpretation gives both the person who stares and herself the benefit of the doubt.

Rebecca noted the need to incorporate a new bodily shape and a different body image into her identity. During our interview, she talked briefly about visually encountering her own body after it had suddenly and drastically changed. Mirrors were very difficult for her at first. This has lessened as time has passed. Even now, however, there are times when she will catch sight of herself in a mirror in a department store or in a ladies' room and be "surprised to see myself looking as I do." This happens less frequently now than it used to. "I do think I am internalizing this new image of myself, this literally new physical image of myself." She finds herself more able to play in the mirror, to make funny faces and dance around—a major change over the last couple of years.

Liz

Liz is a single, European American woman in her fifties who makes her home in Minneapolis, Minnesota along with a dog and a pair of cats. Her dis/ability stems from a spinal tumor appearing in early childhood. She directs an organization which focuses on supporting and encouraging women with dis/abilities in a variety of endeavors from the scholarly to the artistic. Liz describes herself as an advocate for and with people with dis/abilities, particularly women with dis/abilities. She relates her passion for her work to her experience of living with a dis/ability for most of her life and not wanting others to endure what she went through. "Nobody else needs to go through this stuff again.

Nobody else needs to go through people throwing money at you on the streets, because you have a dis/ability. Nobody needs to ever have to wonder whether they can go to the bathroom some place again. Nobody ever needs to wonder whether a program is going to be accessible, or a college, or a movie theater, or whether there's going to be a sign-interpreted performance, or an audio description available, or any of those aspects—transportation, housing . . . churches, by God!"

She admits to having a "temper," which she sees as potentially having both negative and positive outcomes. She sometimes works hard at not saying what is on her mind when her temper flares. At other times, her temper provides the fuel for her work. Liz channels her energy into politically-minded groups in order to push for civil rights and needed services for people with dis/abilities.

Dis/ability does not consume her life, however. Liz is an avid sports fan, especially a "passionate [National Hockey League] lover." Besides setting aside time for professional hockey games, Liz also reserves time for watching college matches, so she can anticipate the NHL prospects for future seasons. She easily lists other joys in her life—a marriage (in the past), friendships, her physical environment, reading, decorating her house for Christmas, music, being the age that she is, having had her particular life experiences. She thinks about writing her memoir. In addition, she has an idea for a children's book on the topic of dis/ability. Liz is engaged in life completely and enthusiastically. One drawback she mentions is lacking the energy she used to have when she was younger. Therefore, she is selective about the activities she pursues. She uses one criterion to determine which interests to follow—they must make her "heart sing."

When asked about her experiences with being the object of stares, she had a hard time coming up with specific examples. The ones she did recall were from her twenties. She explained her difficulty remembering particular incidents by saying, "I've been stared at all my life." She lists the places—at grocery stores, sporting events, shopping malls, on the street. "I'm accustomed to it." She sees being the object of stares as just the way the world is. The effect stares have on her varies. "I can be outrageous about it." Liz tells of one experience when she became aware that someone was sketching a picture of her. She responded by assuming exaggerated poses for the man. At other times, "it can affect me deeply [and I think], oops, I'm really sensitive today." Stares can also be a nuisance, an irritant. Then, she thinks, "take a picture and get on with it."

Her van attracts a lot of attention, too. "I know they're looking at me, staring at me—sometimes it's an icebreaker, but other times I want to close up the van and leave [to] get on with my business." She regularly has people approach her and ask questions about the vehicle. She complains that this interferes with what she is doing. She seems to vacillate between politely acknowledging the inquires and ignoring them. When children are around, "I stuff my impatience. I may be one of the few people with dis/abilities they've seen lately, so I think it's important to leave [them with] a good association."

Liz's advocacy work used to involve frequent travel. In her opinion, Americans are less "bug-eyed" (her phrase) than people from other countries where people with dis/abilities are not as visible. "They really stare, because they haven't seen anything like it—a woman in her chair doing her own thing." Though she tries to be understanding of the context in which other people live, her patience can wear thin. She sometimes wants

to stare back and say, "That's what it feels like—how do you like it?" For Liz, understanding, politeness, and accommodation have their limits. "I was paying a tremendous energetic toll on being nice and not having my needs met." So she decided, "I'm tired of being that way and I'm not going to [accommodate]."

The stare and visibility can easily give way to invisibility. Groups of tourists are especially annoying to Liz, because either they stare or fail to notice her at all. She believes this is because she is "not even a part of their paradigm." Her invisibility combined with politeness became difficult for her to live with. The example she gave was rolling down the sidewalk and seeing a group of folks with cameras around their necks coming toward her and taking up the whole walkway. To accommodate, she would stop and get out of their way. She had no indication that they saw her. She finally concluded, "I have just as much right to be on this sidewalk making my way as [they] do." Now when she finds herself in a similar situation she continues down the path, insisting on sharing the sidewalk.

Liz's dis/ability was part of her childhood experience. Though noting "good stuff" in her childhood, she summed up much of her experience as a young girl with a dis/ability in the phrase, "it was tough." Some of the tough things she had to cope with were humiliation, confusion, loneliness, and exhaustion. One type of humiliating experience involved people on the street coming up to her and giving her money. As her particular dis/ability includes problems with bladder and bowel control, another humiliation could come in not making it to the bathroom in time. Dis/ability can put one in touch with bodily processes that nondisabled people take for granted.

She also experienced confusion as a child. She received odd messages telling her to have faith "like a mustard seed and you'll walk again" from an assortment of people—in notes from her mother's friends or comments from people at church or on the street. She sensed these comments were coming from a place of good will. Nonetheless, she knew her body in a way others tried not to recognize; she knew walking without the aid of braces and crutches was never going to be possible. Her parents did not talk with her about these encounters, which added to her feeling uncomfortable, confused, and frightened. Furthermore, there was disparity between the way her parents saw her and the way she knew herself to be. "My parents really were trying to raise me to be 'normal,' whatever that was, and independent. . . . I knew I was different, yet at the same time I had to *pretend* I was 'normal.'" She felt her life divided into two parts—the medical part of her and the other side of life. Indeed, her life was split into the part spent at a rehabilitation center undergoing treatment and the part spent at home trying to lead a "normal" life. This dichotomy was increased, because these two lives were miles apart, not just figuratively but literally. The medical community which tended to those needs was over a thousand miles from home.

Loneliness was another struggle as a child and a teen. She had friends, but no close friends until later adolescence. Early on, she knew that her dis/ability was linked with difference—emotional and experiential as well as physical, and that her difference meant she did not fit in. In high school the concerns of the other girls were not hers. They talked about boys, dances, and clothes. Her priorities were making it to the bathroom in time and dealing with the exhaustion of walking with braces and crutches all

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day while still needing to get homework done at night, and being angry but knowing it was not considered appropriate to express it.

On the other hand, at the rehabilitation center she did fit in. She was not the only one with a dis/ability and, therefore, there was no expectation to explain it. Dis/ability did not translate into distance between herself and others. No one found a need to attribute religious meaning to her dis/ability. She found not a "we-they" situation but an "us." She was accepted; others, including men, delighted in her; she was comfortable there. "I enjoyed the attention. . . . I felt folks liked me and wanted to spend time with me." Part of the attention included being the doctors' "prize patient." She was selected to talk to nursing students and to help new patients. This also meant that she was "always under the microscope," but it "sure was a lot better than being ignored."

Although part of a church community while growing up, Liz is not now associated with one. As a child, she noticed a discrepancy between words and deeds in the church. "I could never figure out why there had to be steps to an altar and choir loft. . . . If Jesus was here, and he really did say that he loves everybody, then why am I seeing steps in Jesus' house? Jesus knows I can't get up those steps. Why am I here? I don't think this is the place for me—something's not right here. Somebody's lying about something—and it's not Jesus." She described the inaccessibility of churches, in both architecture and attitude, as "misplaced faith." She has a wide range of spiritual interests, has attended workshops and done "a lot of spiritual reading and work," and finds daily devotionals on the Internet.

In some ways, Liz does not see herself as much different from nondisabled people. "I'm sitting here struggling just like everyone else is; my struggle is just a lot

more obvious." She feels uncomfortable when people signal to her that she can go ahead of them in a line.

She does, however, experience a lot of pain at times and feels a lack of sympathy for people who complain about pain. She has developed several ways to deal with pain. Generally, she will simply take two aspirin and move on, trying to distract herself by keeping busy, which, she believes, moves the pain away from herself. She also has a collection of creams and balms that relieve achy joints. If necessary, she will go to bed and nap. "I am more than my body, and my body is also more, and less, than me." She and her body are connected but not identical. Liz thinks of herself and her body as working together in a partnership—"a loving, caring, mindful partnership." She has many plans for her work and her life. She is not inclined to let discomfort get in her way.

Medical and psychological recommendations about bodies run the gamut from ignoring the body to controlling it. Neither is adequate throughout one's life span, though, for some people, either can work in the short run. One aspect of Liz's life experience that others can learn from is her ability to pay careful attention to her body and select a response from a variety of options that have been attuned to her needs and wants and well honed and modified over time.

There are hurts in her past experience, but she has no intention of dwelling on them. In college, she realized she could benefit from therapy, and she worked hard on unresolved issues relating to her dis/ability. She believes hurtful memories are part of the territory of dis/ability. Occasionally, incidents from the past will be triggered by present circumstances. "I deal with them the best way I can." One way Liz deals with these memories is to put them in perspective—as part of her life, but not the whole of it. She

also uses them as motivation to do the work to change circumstances for people with dis/abilities today. Liz looks at life with a wide-angle lens. She recognizes problems in the past as well as hurts and annoyances that erupt in the present, but they are on the periphery of her life. She is focused on the work that has to be done to change the environment for people with dis/abilities. She has many joys in life and has chosen to follow a path that is personally fulfilling. She works to make that a reality for others as well.

It is important to note that the work Liz does occurs in several arenas—one-on-one interactions, changing systems, and providing opportunities that would not otherwise exist. This is a worthy model for persons in ministries of care when dealing with people who have experienced, or are experiencing, stigmatization and marginalization—change can happen in interactions with individuals, through working to alter systems, and by providing new opportunities of growth and accomplishment.

<div align="center">Edie</div>

Edie is a single, European American woman in her late twenties, who lives in St. Louis, Missouri with pets of varying size and species. She uses a wheelchair due to a spinal cord injury that occurred several years before our interview. She was hesitant to commit to a set description of herself; she considers herself to be in flux, becoming a slightly different person moment to moment. However, she was willing to name several characteristics that she thought friends might use to describe her, characteristics that she could acknowledge were fairly consistent over time. She thought her friends might say she was a "thinker." She agreed that thinking is prominent in the way she approaches the world, and that even her emotions are "filtered through some process" involving logic.

She tends to observe her emotional responses before allowing herself to fully feel them. She also said that her friends would probably say that she is "easy-going," "easily amused," and "laugh[s] a lot." She confirmed that she rarely gets angry or loses her temper. Rather than acting on the basis of her emotions, she tries to balance emotional response with a consideration of the perspective of the person who stares, remembering that there have been times in her life when she was that person. When faced with a stare, "I don't know which comes first, but there are two things—obviously, the subjective experience of the different ways it makes me feel, but just as strongly, just as quickly, I also think of the reasons that people stare. . . . Even if it's making me uncomfortable at that particular time, it's not without understanding, without compassion." Edie named several reasons why she thinks people stare—out of curiosity about or unfamiliarity with dis/ability, to create or acknowledge difference, due to surprise at the unexpected, and in order to help. These are not necessarily discrete categories and variations exist within each one.

Like Rebecca, Edie named curiosity as a reason people stare. They are curious because of "ignorance" about dis/ability. This lack of knowledge can also lead people to fail to notice her or certain things about her. Edie thinks people are curious about her because, as a wheelchair-user, she looks "novel" or "unusual." Edie tells a story about her own experience of staring at a woman who looked different from anyone she had ever seen before. "My sense of myself and how I was acting—it was just gone. . . . I guess I couldn't help myself—I was not aware of anything [else]. . . . I had no sense of what I was doing." When she realized she had been staring at this woman, she became extremely embarrassed. Her face even turned red as she told me about the incident. "I

felt *terrible* that I had done that. I felt so embarrassed that I had acted so rudely. . . . But I

didn't have any bad intentions in doing it—it was curiosity." When she thinks about the

act of staring, she remembers that she, too, has been guilty of it. Though she terms her

staring behavior "rude," she remembers that it was not her intention to be unkind. She

was seeing someone who looked novel, someone who had characteristics with which she

was unfamiliar.

The idea that dis/ability is a novelty is somewhat puzzling. Estimates suggest that

there are over 200,000 people with spinal cord injuries in the United States today, with

about 11,000 persons added to that number each year.[12] High profile people who have

spinal cord injuries include actor Christopher Reeve and reporter John Hockenberry.

Spinal cord injuries are not rare. People who use wheelchairs are not rare. A booklet

published by the National Organization on Disability states that "54 million Americans

[are] estimated to have disabilities," "1.4 million are wheelchair users," and this number

does not include the "millions of others who use walkers, canes, braces or crutches."[13] It

also does not include the many others who have mobility dis/abilities but use no

equipment. What is curious is that people lack knowledge about a group of people that

numbers in the millions. What seems as if it is benign curiosity likely has its roots in

cultural practices such as warehousing of people with dis/abilities in nursing homes,

keeping relatives with dis/abilities out of sight, creating inaccessible social and

architectural structures, and passing ordinances that required some people with

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[12] "Facts and Figures at a Glance—December 2003," *Fact Sheet*. Birmingham, AL: National Spinal Cord Injury Statistical Center, 2003; online, accessed 25 Mar. 2004; available from http://www.spinalcord.uab.edu/show.asp?durki=21446&print=yes.

[13] Ann Rose Davie and Ginny Thornburgh, *That All May Worship: An Interfaith Welcome to People with Disabilities*, ed. Ginny Thornburgh (Washington, D.C.: National Organization on Disability, 2000), 20.

dis/abilities to avoid public places. The "curious stare," though connected to lack of knowledge and perhaps less offensive than blatant prejudice, is no less influenced by cultural assumptions and barriers.

Edie attributes people failing to notice her, in particular, disregarding her as a possible date or potential partner to a lack of understanding about dis/ability. Before she broke her back, "I was dating like crazy." Now dating has changed. "I don't appear as a sexual being to most people." She feels as if she automatically gets put into a "little sister" or "just friends" category. She believes that men are much less willing to consider dating her. There is a part of her that misses men finding her attractive and desirable on sight. "They have to know me now. They have to have some sort of confidence that it would be worthwhile, worth any trouble it might involve." She acknowledges that it requires extra energy to go out with her, for example, getting wheelchairs in and out of cars can be complicated. She experiences this herself when she makes arrangements to go to dinner with friends who also use chairs. She concludes that, for a nondisabled person, a lack of knowledge about such matters likely seems "daunting." She also believes that nondisabled people lack knowledge about sexuality as it relates to a woman with a dis/ability. Edie states she understands this ignorance, because sexual capacity differs with each person and depends upon the particularities of the woman's dis/ability. But, she says, this lack of understanding, whether about sexuality, or loading chairs into a vehicle, or any other matter, can be bridged, and "it's not that big of a bridge." She believes that, unfortunately, both women with dis/abilities and the people they would like to date often lack the knowledge of what it takes to build that bridge and the ability to communicate about it.

As with most things, Edie views the dating issue from a number of angles.

Having recently "untangled" herself from a difficult relationship, she says she is not at

the moment interested in another relationship. Therefore, she is mostly content to be left

alone. She has friends with dis/abilities, though, who are distressed about being excluded

from romantic relationships. Edie notes, on the positive side, that "it [dis/ability] weeds

out a lot of [unsuitable] people." Unfortunately, it may have "weeded me out of other

people's lives" who might have been people she would have enjoyed.

Conversely, there are some people who, rather than being discouraged, are drawn

to dis/ability. Edie mentioned that she has met some "weird" men with "weird fetishes,"

one of whom was oddly attracted to her wheelchair, frequently saying, "Your wheelchair

is so beautiful." She makes faces indicating distaste while recalling this interaction.

There are times, however, when Edie neither wants to be left alone, nor is willing to wait

for bridges to be built, times when she wants to express her sexuality and be noticed.

Occasionally, she enjoys flirting and will initiate it. She gets surprised responses but

often positive ones.

In Edie's experience, the stare—including her stare—can create or acknowledge

separation and difference. She recalls times when she is driving her car (and, therefore,

not using her chair), has seen someone out the window using a chair, and rejected

identification with that person. "It's this feeling of separation, of difference—'I'm not

like that.' That's something important to me to remember when I'm feeling

uncomfortable because somebody's looking at me strangely." This feeling of difference

can extend to a sense of not belonging, that is, not belonging to the dis/ability category,

which can come from her or another. When she returned to the university following her

accident, she learned that some students thought she did not belong in the chair, that she must be using it for a class to experience what it would be like. She sometimes catches her reflection and thinks she does not belong there. At other times, when she is pulling into a handicap parking place, she notices other people eyeing her with suspicion, thinking that she does not belong in those places, until she puts her blue handicap placard in the window.

For Edie, staring and not belonging do not always include distancing. She has experienced stares as an indication of attraction. As an exchange student the year before she became disabled, she was in a country where she looked very different from most of the people. She received a great deal of attention, which she thoroughly enjoyed. Though difference, especially in relationship to dis/ability, often translates into distance, difference itself does not need to result in distance and separation. Because of the stares she received as an exchange student, Edie finds ways to view the stare as a means of getting attention, with the possibility of it being positive attention.

Some of the stares directed at Edie, she believes, are coming out of surprise, surprise that she can do the things she does. She thinks people are surprised that she is smart. She recalls an incident in the rehabilitation hospital when someone began a conversation with her mother, speaking about Edie in the third person, while Edie was present. The person assumed that Edie's physical dis/ability indicated a cognitive dis/ability as well. In college, she experienced other students staring at her out of surprise that she was articulate in response to teachers' questions and that she scored high on exams.

People express surprise at her physical abilities. Strangers do not seem to expect her to be able to maneuver her chair in and out of the car. Friends are amazed when she rearranges her furniture by herself. She experiences people expecting less of her or having no expectations of her at all. These reactions are different from the ones she got when she was a nondisabled person. "When you're able-bodied, people expect you to do things, and you expect yourself to do them." It was a shock for her to realize, about a year after her accident, that her parents were doing things for her, for example, changing channels on the television, that she could do herself. She decided to push herself to see what her limits were and not to let others do for her what she could do for herself.

People are often reminding her, through their offers of help, that it is assumed that she is unable in many ways. Many of these offers Edie finds "insulting, in general." However, because she is not dealing with attitudes in general but with particular people in specific encounters, she chooses not to take offense at them. She responds to "ridiculous," i.e., inappropriate and unnecessary, offers of help with a matter-of-fact "No, thank you" and is content, even proud, to surprise people with what she can do. Her underlying philosophy of life is that offering help to someone who needs it should be encouraged. "I don't think it's ever a good thing to thwart someone's efforts to help." Nonetheless, she hopes her polite refusals of help, accompanied by the demonstration of her ability, will lead to increased awareness. The message she hopes people learn is: "Don't be insulting; don't assume." The Buddhist understanding of "skillful means" informs her position. There are right ways of assisting others. "The idea behind [skillful means] is your intentions may be good . . . [but] more important than just your intentions

[is] the effect, the consequences of your actions—they may be a lot more harmful than you realize, than you intended them to be."

Edie's explanation of the Buddhist idea of *skillful means* has similarities with some ministries of care. Both suggest that the effect of a certain practice on the receiver of that care is a factor in assessing the appropriateness of the care offered. Well-intentioned people who initiate assistance when none is needed do Edie a disservice rather than aid her. Practices of care are most effective when they are attuned to the particularities of the persons receiving care. Edie's advice is good—"Don't assume." In other words, check it out; ask what a person needs and proceed accordingly.

Edie challenges the view that she, as a woman with a dis/ability, is marked by inability, and she does so by discovering the extent of her own abilities, as well as demonstrating those to others. This has proved extremely positive for her. However, the task of continually contesting inaccurate views was also causing her a problem at the time of our interview. Edie was in the process of moving from one apartment to another. She needed help unloading her car at her new place but was hesitant to ask for it. She had not minded asking for assistance from friends at her old apartment but was finding it impossible to ask new acquaintances for help. It is a dilemma. If any show of need exacerbates the image of dis/ability as inability, then asking for help has the potential of undoing all one's hard-fought battles to emphasize and gain recognition for one's capabilities.

Rethinking Embodiment

The profiles of Joanne, Camille, Rebecca, Liz, and Edie reveal cultural assumptions made about individuals based solely on the way a person's body looks or

moves. Such stereotypes can lead to practices of exclusion and diminishment and, thus, denial of full personhood. The profiles also show women whose lives challenge society's views about dis/ability. Pastoral theologians who work at the intersection of human experience, practices of care, and theological and religious inquiry are in a unique position to enter into a conversation about embodiment and a rethinking of theories, theologies, and practices. Persons in ministries of care and counseling are in a position to hear the untold stories, embrace new interpretations and understandings of embodiment, and revise pastoral practices, thus working toward the goal of engendering the full humanity of everybody.

Scientific, consumer, and popular cultures have created an image of what bodies should look like and what bodies should do. Women with dis/abilities (among others) do not fit this image. The stare symbolizes a cultural awareness or judgment of deviation from that image. Cultural representations and social practices would have us believe that women with dis/abilities do not fit the image due to flawed bodies. However, the dominant view of the human body is inadequate, because it does not include the bodies of women with dis/abilities. If the cultural image is flawed, if the theories and theologies about embodiment fail to reflect the lived bodily experience of people with a variety of physical configurations, then it is time to reinterpret, revision, and transform those theories and theologies, and the practices of care with which they are associated.

A pastoral theology of embodiment that includes all bodies, that is, engages the reality that human variation is immense, and that fully human bodies come in many configurations, contributes to the on-going dialogues about theological anthropology, inclusion, and the practice of care. The dis/ability rights movement is challenging

society's assumptions about and policies for people with dis/abilities. Change is necessary in the church, too, because faith traditions have participated in the exclusion and diminishment of both women and persons with dis/abilities. The creation of new practices to supplant the old is called for. Practices include listening to the stories which report and challenge biased cultural representations, caring for those who are hurt by exclusionary practices, broadening the perceptions of those who participate in exclusionary practices, expunging the cultural assumptions and expectations (but widely believed by both nondisabled people and people with dis/abilities) out of all our psyche-souls, and creating communities of faith where all persons belong.

This chapter is set in the context of the lives of these five women. In the following chapter, the context changes. Just as the stare is embedded within the narratives of individual lives, individual lives are embedded within the narratives of a particular culture. I will continue to explore the stare, not as it functions in a particular life, but rather in the symbolic form of the oppressive gaze, which functions to shape cultural representations. I will move from a suggestion to reformulate theologies of body to an argument for the goodness of all bodies. I will tell few particular stories but, seeking alternative narratives, will examine the challenges women with dis/abilities face in light of dominant cultural representations of "woman" and "dis/ability."

CHAPTER 4

CULTURAL REPRESENTATIONS: A MATTER OF APPEARANCE

The previous chapter presented narratives of the stare in the context of individual women's lives. This chapter focuses on the lives of women with dis/abilities within the context of the wider society. Cultural views about the body and the ways women with visible dis/abilities are perceived in consumer and scientific cultures are a matter of appearance. In three sections, this chapter examines the role appearance and representations of "woman" and "dis/ability" play in social and religious attitudes toward women with dis/abilities. The first section, "The Formation and Character of Cultural Representations," describes how the high value given to the concept of "normal" in bodily appearance translates into devaluation for bodies with dis/abilities. In the second section, "The Goodness of All Bodies," I argue that bodies, all bodies, are good. The third section, "Physicality and Representations of 'Woman' and 'Dis/ability,'" discusses the convergence and collision of representations of "woman" and "dis/ability." Particularly damaging are the contradictory images of woman as striving for perfection and dis/ability as permanently defective.

The Formation and Character of Cultural Representations

People make judgments based on appearances. Those judgments may be positive or negative and often contain very specific assumptions. Some people see a tall person and think she must be good at basketball. In Joanne's case, people sometimes assume that she is cognitively disabled, because she has a physical dis/ability. Factors related to the formation, content, and continuation of representations of dis/ability that are dominant in the United States rest heavily upon the concept of "normal." Cultural

representations are images with cultural meaning. The presentation of such an image

conjures up thoughts, feelings, and assumptions that have become attached to that image.[1]

Cultural representations are social constructs that, once they take hold in a culture, take

on a life of their own. The eye begins to see what it expects to see and has been

socialized to see, rather than what is present. Fortunately, alternative narratives

sometimes emerge.

The Creation and Tyranny of Normalcy

Edie believes that one reason people stare at her is because they think she looks

"novel." The idea of appearance as novelty assumes that there is an "ordinary" or a

"common" way of being a human body in the world. A person looks "novel" compared

to the "ordinary." Indeed, industrial cultures have imaged humans according to

statistically average physical characteristics and crafted the physical environment to

accommodate this standardized form of the human being. Airline seats are a good

example. As a person who is shorter than average, my feet barely, if at all, touch the

floor when sitting on an airplane, placing uncomfortable pressure on my knees.

Likewise, I have noticed persons who are taller than average crammed into an airline seat

with their knees almost touching their chests—equally uncomfortable. The statistically

average body is considered the norm and bodies other than average are judged "novel."

Bodies that differ from this average body may be defined as above normal or

below normal. Though both above normal and below normal are not "normal," that is,

they are statistically "abnormal," differing values are placed on those conditions. Bodies

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[1] For further reading about women and representation, see Laura Mulvey, *Visual and Other Pleasures* (Bloomington: Indiana University Press, 1989). For reading about representation and bodies, especially disability, see Rosemarie Garland Thomson, *Extraordinary Bodies* (New York: Columbia University Press, 1997).

that are "above normal" are rarely considered abnormal but are usually admired and considered superior. "Abnormal" is not simply descriptive of a bodily characteristic that is not statistically average but, rather, connotes "below normal," an undesirable condition. Bodies with dis/abilities are generally identified as "abnormal" and are disvalued.

The idea of bodies with dis/abilities as not measuring *up* to "normal" physical standards is a relatively new way to configure dis/ability, according to dis/ability scholar Lennard Davis. Davis asserts that it was in the construction of normalcy that the idea of the disabled body was formed.[2] "The word 'normal' as 'constituting, conforming to, not deviating or different from, the common type or standard, regular, usual' only enters the English language around 1840."[3] "Normal" was followed by "norm," "normality," and "normalcy" within twenty years. Thus, the "disabled body" defined whatever was "excluded from culture, society, the norm."[4]

The fields of statistics and astronomy played a role in determining both the norm and its exclusions. Statisticians began applying their mathematical formulas to the human body in the early nineteenth century. One French statistician, Adolphe Quetelet, used astronomers' method for locating a star to construct the features of the average man.[5] When astronomers plotted the sightings of a particular star, a bell-shaped curve resulted, with the most accurate locations closer to the center and the least accurate, the

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[2] Lennard J. Davis, "Constructing Normalcy: The Bell Curve, the Novel, and the Invention of Disabled Body in the Nineteenth Century," in *The Disability Studies Reader*, ed. Lennard J. Davis (New York: Routledge, 1997), 9-28.
[3] Davis, 10.
[4] Davis, 11.
[5] Davis, 11.

extremes or the errors, further away.[6] Eugenicist Sir Francis Galton (Charles Darwin's

cousin) decided that, in human beings, both extremes from the norm, that is, from the

center of the bell-shaped curve, were not equally deviant. Certain human characteristics

appeared preferable to him, so he turned the bell-shaped curve into a system of quartile

rankings.[7] Therefore, one set of deviations from the norm became valued as above

normal while the other set of deviations retained the "deviant" or "error" labels.

Eugenicists, sparked by Darwin's theory of natural selection, believed that bodies could

be altered intentionally to maximize preferred characteristics. Therefore, they began to

devise schemes to "improve" the human species by eliminating from the gene pool

people who were identified as having such diverse characteristics as low intelligence,

dis/abilities, mental illnesses, criminality, and sexual license.[8] Compulsory sterilization

was one method used.[9]

From this history comes the concepts of normal and abnormal, the idea of

dis/ability as deviance, the habit of lumping together humans with diverse characteristics,

and the search to eliminate people with certain "undesirable" features. Thus, physical

dis/ability, rather than being seen as one of many human variants, is labeled abnormal

and deviant, invested with multiple negative connotations, and constructed as a problem

that needs to be solved or repaired. This heritage plays itself out in the stare and other

devaluations of difference, in the creation of environments based on concepts of the

average body, and in cultural representations.

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[6] Davis, 11, 13.
[7] Davis, 16.
[8] Davis, 17-19.
[9] Deborah Marks, *Disability: Controversial Debates and Psychosocial Perspectives*
(London: Routledge, 1999), 35.

The perception of dis/ability as an abnormality that must be eliminated is highlighted by that staple of some charitable organizations—the telethon. The poster child becomes the epitome of helplessness and an object of pity. Jerry Lewis and his imitators use that pity to appeal to the viewing public for large sums of money, with the promise that scientific research can lead to the engineering of "normal," or even ideal, bodies for all people. "Normal" and "perfect" become fused together.

The "us" and "them" mentality of "normal" and "abnormal" designations is highlighted by "freak shows," which put people with dis/abilities on display.[10] For a few coins the public could view the bodies of people with physical variations unfamiliar to most people. The more infrequently the variation occurred, the greater the draw. The freak show is a part of the common societal heritage of people with dis/abilities (the observed) and nondisabled people (the observers).

Even though nondisabled people paid money to see people with dis/abilities in a freak show, they did not want them out and about in town. A 1911 city of Chicago ordinance reads: "It is hereby prohibited for any person who is diseased, maimed, mutilated, or deformed in any way so as to be an unsightly or disgusting object to expose himself to public view."[11] Referred to as "ugly laws," some stayed on the books until the 1970's.[12]

People with dis/abilities bear a stigma. Sociologist Erving Goffman identifies three major types of stigma, attributes that "mark" a body. The first of these is

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[10] See Eli Clare, *Exile and Pride* (Cambridge, Mass.: South End Press, 1999), 71-87; and Thomson, *Extraordinary Bodies*, chap. 3, for more information on "freak shows."

[11] *Staring Back*, ed Kenny Fries (New York: Plume, 1997), frontpiece.

[12] Thomson, 7.

"abominations of the body—the various physical deformities."[13] Goffman observes that "[b]y definition, of course, we believe the person with a stigma is not quite human."[14]

Discrimination toward people with dis/abilities did not begin with the creation of statistics, eugenics, and the concept of normalcy, but the form it currently takes is produced, in part, by the thought and social movements associated with those efforts. Some of the labels or features of cultural representations of people with dis/abilities that relate to the idea of normalcy include abnormal, irregular, unusual, and deviant. The exclusion, modification, or elimination of people with disabling characteristics are legacies of industrial society.

Despite the high value the dominant narrative in the United States places on normal or above normal bodily features and the lower value attached to bodies which fall short of "normal," the statistics of a woman's body do not represent an accurate measure of her life, experience, humanity, or worth. A pastoral theology of embodiment argues and advocates for the positive value of all bodies, no matter where each body falls on the arbitrary quartile ranking of science.

The Stare as Oppressive Gaze

Bodies that are "different," that depart from the statistical average, are subject to being an object of others' staring activity. Staring is about seeing and being seen and about not seeing and not being seen. There are a number of terms that can be used to describe the way one person looks at another. Roget's thesaurus lists dozens of words

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[13] Erving Goffman, *Stigma* (Englewood Cliffs, N.J.: Prentice Hall, 1963), 4. The other two types of sigma Goffman notes are "blemishes of individual character" and "the tribal stigma of race, nation, and religion."

[14] Goffman, 5.

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which are synonyms for "looking," as in "to examine visually."[15] Sometimes, however,

what we examine and assume to be visible is invisible; what we think we know is partial,

because our vision is limited.

The "oppressive gaze" has this characteristic of restrictive vision. The oppressive

gaze is a way of seeing that (re)creates and symbolizes the person at whom the gaze is

directed. The oppressive gaze sees selectively. It sees what it is expecting to see, that is,

it sees what it has been taught to look for. In seeing what it was looking for, it creates

anew what has already been created. The oppressive gaze confirms what the gazer

already thinks she knows. This gaze is a vehicle of objectification—what it looks at is

not so much a person, not a being with whom one relates, but an object to be observed. It

watches in order to size up, to measure, the object according to the dimensions society

has already established. In addition, what the oppressive gaze sees contains unverified

assumptions. Because it sees only what it is looking for, it takes for granted that what it

sees is all there is. It fails to look further.

> For the most part, our vision conforms, conforms to the gaze of a social order
> which reflects and multiplies our fears, ignorance and passions, and which
> extinguishes many of the sparks that might otherwise kindle some effort of
> vision.[16]

The multiple possibilities of taking in the other are cut short.

There are three forms, or contexts, of the oppressive gaze at work in the stare as it

relates to women with dis/abilities. Literature related to dis/ability refers to two—the

oppressive gaze aimed at persons with dis/abilities and the gaze of medical professionals.

Feminist writings are critical of the oppressive gaze directed toward women.

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[15] *Roget's 21st Century Thesaurus*, 2nd ed., s.v. "looking."
[16] David Michael Levin, *The Opening of Vision* (New York: Routledge, 1988), 56.

The Oppressive Gaze and Dis/ability

The oppressive gaze, upon sighting a person with a dis/ability, focuses on the dis/ability and casts the person as dis/ability. Thus, it creates in that person, in that moment of seeing, the cultural representation of a disabled figure that has already been constructed and transmitted by society. The cultural representation fails to reveal the complexity and wholeness of the person to whom it is applied.

Bill Hughes, a dis/ability scholar from the United Kingdom, describes and analyzes the oppressive gaze as an event that results in the "constitution of impairment."[17] He challenges modernity's focus on the senses, especially sight, as presumably unbiased ways of perceiving external objects. "It [the discriminatory gaze] fails to recognise its own partiality and assumes, without warrant, the absolute clarity of its own vision."[18] Rather, Hughes contends, vision is not neutral. It is disfiguring and discriminatory. It is an act of judgment and domination. Perception interprets and, thus, constructs the disabled body as other, as stranger.[19] "Bodies are not simply seen, they are also read, and read through categories that place them in a hierarchy of bodies."[20] Persons who gaze exercise power and control over another, transforming the object of the gaze into spectacle. Persons who gaze use the gaze to define the other for themselves.[21] Hughes argues that taking command of the visual field allows the powerful to constitute the other as stranger, to validate and invalidate, and call it truth. This is reminiscent of Thomson's

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[17] Bill Hughes, "The Constitution of Impairment: Modernity and the Aesthetic of Oppression," *Disability and Society* 14, no. 2 (1999): 155-72.
[18] Hughes, 164.
[19] Hughes, 157, 160.
[20] Hughes, 163.
[21] Hughes, 163.

statement that "the stare sculpts the disabled subject into a grotesque spectacle."[22] Such crafting results in discrimination, aversion, exclusion, and sometimes, as I argue in the next chapter, annihilation for persons with dis/abilities. Hughes contends that this relationship between the nondisabled and people with dis/abilities will continue "until the constitutive gaze is appropriated by those who have been condemned by it."[23]

Change or transformation becomes a possibility when those who have been the object of the gaze become subjects in defining themselves. Rejecting the dominant narrative, people with dis/abilities write alternative narratives, such as those presented in chapter 3, that challenge the paradigm for dis/ability as described by nondisabled seers.

The Oppressive Gaze and the Medical Specimen

A second form of the oppressive gaze related to women with dis/abilities is the medicalized gaze. This type of gaze (re)constructs the individual as a medical specimen and/or an opportunity for experimentation. Most women with dis/abilities have contact with the medical community. All five of the women I interviewed made reference to doctors, hospitals, surgeries, or rehabilitation centers. For some, this figured prominently in our conversation or in the stories of their life experiences. For others, it was a footnote in the interview. The stare of the woman or man on the street is multiplied exponentially in the medicalized gaze. The person on the street may eventually become embarrassed and avert her or his eyes, but the medical professional can maintain the stare as long as she or he wants, without embarrassment, and is paid to do so.

The medicalized gaze accentuates the cultural view of the body with a dis/ability as "abnormal," "deviant," and "disorderly." The medical professional searches for

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[22] Thomson, 26.
[23] Hughes, 163.

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pathology—the "normal" is of interest only as a comparison.[24] The power differential is

clearly defined in the medicalized gaze. The medical professional is assumed to have

expertise about the bodies of women with dis/abilities. It is expected that a woman with

a dis/ability will follow the advice of the expert. The primary goal of the medical

professional is to change, if at all possible, the other's body, based on what the

medicalized gaze determines is "wrong."

It can be a dehumanizing, even humiliating, experience to have certain parts of

one's body scrutinized so intensely, and for many people with dis/abilities, this

confrontation with the medicalized gaze begins at a very young age. Marsha Saxton has

written about her early childhood experiences and recalls, when hospitalized, fearing the

doctors' rounds—the medicalized gaze of a group. The children, covered only by a

"white canvas bikini," were paraded in front of the doctor-spectators.[25]

> One [doctor] would call me over to him and he'd flex my feet up and down, and
> command me to stand on my toes, to stand on one foot, to bend my knees. How
> hard I'd try to do it right, so maybe they'd leave my body the way it was. Maybe
> they wouldn't make me have surgery.[26]

In contrast, the medicalized gaze can occasionally be a source of positive

attention. Liz, who had multiple surgeries as a child and teen, received attention as a

"prize patient," which she enjoyed. It was not, however, without costs. She was "always

under the microscope . . . being examined and looked at." She described herself as

"rebuilt from shoulders down to feet and back up again." The (re)construction of the

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[24] Medical professionals include a large number of persons with a variety of specialties and views on dis/ability. Some persons are very much a part of the dominant paradigm, which focuses on pathology and correction. Others are allies of people with dis/abilities or have a dis/ability themselves and take an alternative approach.

[25] Marsha Saxton, "The Something That Happened before I Was Born," in *With Wings*, ed. Marsha Saxton and Florence Howe (New York: Feminist Press at the City University of New York, 1987), 51-55.

[26] Saxton, 54.

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object in the medicalized gaze can be a literal, physical event as well as a social phenomenon.

The Oppressive Gaze and Woman

Women have also complained of the oppressive gaze, also referred to as the male evaluative gaze in feminist literature.[27] The oppressive gaze looks at a woman and (re)creates in the viewer's mind the cultural representation of woman, which may have little to do with the actual woman who is the object of the gaze. Though the constitution of woman is equally as objectifying as the construction of dis/ability and the medical specimen, the content is different.[28] The human male is the subject with the power to construct, and the female representation is constructed and reconstructed as the male sees and reads her through body categories.[29] According to feminist theorist Teresa de Lauretis, "[t]he representation of woman [is] spectacle—body to be looked at, place of sexuality, and object of desire."[30] Woman, like dis/ability, is a spectacle but not a grotesque one. Rather, the cultural representation is exactly opposite to that of dis/ability. Consumer culture expects women to be attractive, desirable and, therefore, the object of the male gaze. Women are to be seen and enjoyed. Feminist film critic Laura Mulvey calls this "pleasure in looking."[31]

Women are given countless messages about what the female body should look like and for whom. Catharine MacKinnon writes about women learning gender socialization. "Socially, femaleness means femininity, which means attractiveness to

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[27] That the gaze is a male gaze directed at a female reveals both the traditional hierarchy between men and women and the heterosexist bias of Western culture.

[28] Teresa De Lauretis uses "woman" to designate a representation, a "fictional construct." Teresa De Lauretis, *Alice Doesn't* (Bloomington: Indiana University Press, 1984), 5.

[29] De Lauretis, 161.

[30] De Lauretis, 4.

[31] Mulvey, especially 14-26.

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men, which means sexual attractiveness, which means sexual availability on male terms."[32] So, whereas both dis/ability and woman are Other, to the one with the power (either the nondisabled person or man), the one who stares tries to create distance between her- or himself and the person with dis/abilities but wants to draw the attractive, nondisabled woman closer.

This complicates matters for nondisabled persons as well as for women with dis/abilities. Nondisabled people may have a hard time holding both woman and dis/ability together. If "normal" is the ideal, those lacking the characteristic "normal" are configured as different, as abnormal. If "normal" means an orderly body, dis/ability is ascribed disorder. If "normal" confers validation, dis/ability confers invalidation.[33] If the cultural representations of nondisabled women include sexual attractiveness, desirability, and femininity, the representations of women with dis/abilities connote unattractiveness, undesirability, and a lack of femininity. As noted in chapter 3, Edie, who frequently drew the male gaze before her dis/ability, reported that following her accident, she was placed in the position of "just friends" or "little sister" with male acquaintances, but rarely a romantic interest.

The (re)constitution of cultural representations takes place through the oppressive gaze, which makes a spectacle of "dis/ability," "medical specimen," and "woman." All these images evoke some idea of "normal," whether one is seen as embodying it or deviating from it.

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[32] Catherine A. MacKinnon, "Feminism, Marxism, Method, and the State: An Agenda for Theory," *Signs* 7 (Spring 1982): 530-31 as quoted in De Lauretis, 166.
[33] See Hughes.

The Goodness of All Bodies

The idea that bodies, or certain bodies, are *no good* can be challenged. In the United States, people discard items that are no good or no longer good, food that is spoiled or clothes that are worn out. Unfortunately, most churches also discard people with dis/abilities by failing to make a place for bodies that are unlike society's idea of "proper" or nondisabled bodily configuration. If something that is no good is for throwing away, then "good" is a word applied to an object we regard favorably in some way. But, what criteria do we use to determine if something is good? Nostalgia? Social values? Cherished by God? The thesaurus has dozens of synonyms for "good," and the dictionary has over fifty definitions.[34] Many of these definitions or synonyms could be applied to the five women I interviewed and to other women with dis/abilities. As a term of positive valuation, the word "good" can refer to something that is sufficient or adequate for a particular purpose. The bodies of women and men, with and without dis/abilities, *are* sufficient for the purpose of living into the fullness of life. We are capable of moving toward living fully in whatever bodies we have. Our bodies are good.

To regard bodies favorably challenges the stare. To claim that the body is good, that any body is good, that those bodies marked by characteristics consumer and industrial cultures deem "lesser" are good, is a radical claim, and one that is crucial for the well-being and wholeness of women with visible dis/abilities. A theological claim that all bodies are good challenges practices of exclusion. In the epistle credited to James, the writer exhorts those who confess God's presence in the person of Christ Jesus

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[34] *Roget's 21st Century Thesaurus*, 2nd ed., s.v. "good." *Webster's New Universal Unabridged Dictionary*, s.v. "good."

to show no partiality.[35] The writer is referring to the early believers who treated the

wealthy with greater respect than the poor. However, the passage is equally applicable to

other disvalued groups, including women with visible, physical dis/abilities.

Christian texts, like Christian traditions, have conflicting views of the body. Two

passages from Leviticus,[36] for example, deny the goodness of certain bodies, stating that

some skin disorders are a manifestation of God's punishment and that persons with

certain physical characteristics, some of which are dis/abilities, are forbidden from

entering the Holy of Holies. Scripture, however, as well as culture, has dominant

narratives and alternative narratives, dominant interpretations and alternative

interpretations. The Christian tradition also affirms the goodness of creation. In the

beloved narrative that begins the Hebrew scriptures, we find God creating all kinds of

bodies—bodies of water and areas of dry land, plants and trees, light producing bodies,

creatures of the air and sea and land, and human bodies—female and male. One

theological claim made in Genesis 1-2.4 is that creation has immense variety and is

judged good.[37] Biblical scholar Walter Brueggemann stresses that "creation is

characterized by God's delight."[38] This delight extends to each human being. "Human

persons are honored, respected, and enjoyed by the one who calls them to be. And this

gives human persons their inalienable identity."[39]

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[35] James 2.1-13.
[36] Lev. 13-14 and 21-22.
[37] Brueggemann differentiates between a historical claim and a theological one. Walter
Brueggemann, *Genesis* (Atlanta: John Knox Press, 1982), 26.
[38] Brueggemann, 27.
[39] Brueggemann, 31.

In addition, Brueggemann's exegesis of this passage acknowledges the reality of chaos.[40] Genesis 1-2.4 is believed to have been addressed to persons living in the unpredictability of exile.[41] Living with a dis/ability can be akin to living in exile, a resident alien in one's own country and own family. The body of a person with a physical dis/ability may be configured in a way unlike anyone else she knows. Her actions may be different from other people living nearby—in the way she talks or moves or the daily routines she performs. People often treat the person with a dis/ability differently from a nondisabled person and ask questions they would ask few others. "Disabled people are asked 'How did you get like that?' and 'Can you be cured?'. Both questions interpolate an 'outsider', someone whose existence presents a problem to the fully-fledged citizen."[42] Genesis 1 reminds us that chaos has not been eliminated. The possibility of exile remains.

Throughout Christianity's sacred texts, the Creator continues to bring new things to life—to turn hearts of stone into hearts of flesh, to provide for the basic needs of all people, and to welcome the marginalized into community. The presence of chaos in Genesis 1 acknowledges the unfinished nature of earthly life and offers hope for the transformation of unjust social structures as God, joined by the people of God, continues the process of creation and re-formation.

The early chapters of Genesis present a second creation narrative in which the Creator fashions a human, "man," from the earth and creates another human, "woman,"

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[40] Brueggemann notes the ambiguity in the text of creation from nothing and creation as ordering of chaos and states that the text is richer for the theological affirmations made possible by this ambiguity. See pages 22-39, esp. 29-30.

[41] Brueggemann, 25.

[42] Marks, 28.

from the rib of the first. This narrative moves seamlessly from creation into disobedience, referred to as the "Fall" of humankind. Creation's link with the "Fall" has been harmful for people with dis/abilities because, as theologian Dawn DeVries points out, this linkage is used to support belief in an "original perfection" of the world "beside which all impairment and disease are seen as evil deviations—the result of sin."[43] This view assumes that disability was not part of God's originally perfect world but "a perversion of it. . . . either willed or allowed by God."[44] DeVries questions the concept of an "original perfection" and its application to humans. "[I]t is difficult to imagine what would be the definition of a 'perfectly normal' person."[45] It is necessary neither to posit an originally uniform and perfect creation nor to include a story of a "Fall" as intrinsically connected to narratives of creation in order to proclaim that a good God is the source of a good creation that includes finitude, limitations, and difference.

Living with dis/abilities can be chaotic and unpredictable. Yet, in the midst of limitations and uncertainty, God delights in creation. In telling and retelling the creation story, Christians attest that creation is varied and valued by the Creator. The bodies of women with dis/abilities are neither statistically ideal, nor unproblematic, nor always predictable, but they are cherished by the Source of Life, and that means we can pronounce them good.

Appreciating atypical bodies is challenging when the cultural definition of beauty for women is so narrow and has no place in it for women with dis/abilities. Womanist

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[43] Dawn DeVries, "Creation, Handicappism, and the Community of Differing Abilities," in *Reconstructing Christian Theology*, ed. Rebecca S. Chopp and Mark Lewis Taylor (Minneapolis: Fortress Press, 1994), 127.
[44] DeVries, 135.
[45] DeVries, 136.

sociologist Cheryl Townsend Gilkes describes as "cultural humiliation" the oppression

faced by African-American women when standards of beauty for women in the United

States most closely follow the body type of a thin white woman.[46]

Women with dis/abilities face a similar cultural humiliation, because this

prototypical ideal woman also walks unaided and carries her body gracefully as she

moves along. She is probably also athletic, involved in activities such as weight training,

kick boxing, running and, one of the latest crazes, "spinning." She does not use a

wheelchair, walker, scooter, cane or crutches, nor does she wear a prosthesis or brace. If

she is an exception to this rule, such as the wife of singer Paul McCartney, Heather Mills

McCartney, who had part of her leg amputated due to an automobile accident, her

dis/ability is almost always mentioned whenever reference to her is made.

Gilkes argues that women who most nearly approximate the North American

norm of female beauty are offered advantages that other women are not.[47] But Gilkes

finds in Alice Walker's description of womanist a method of resisting the

dehumanization inherent in unattainable cultural norms—love the body you have. "[I]n a

society that pulls its various cultural hatreds together in such a way as to destroy and

victimize Black women, Walker passionately emphasizes the importance of self-love.

'[A womanist] loves herself. *Regardless*.'"[48] Ignoring cultural values about what bodies

should look like, women with dis/abilities can, and often do, love their bodies. Persons in

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[46] Cheryl Townsend Gilkes, 'The 'Loves' and 'Troubles' of African-American Women's Bodies," in *A Troubling in My Soul*, ed. Emilie M. Townes (Maryknoll, N.Y.: Orbis Books, 1993), 233-36.
    [47] Gilkes, 235-36.
    [48] Gilkes, 239, referring to Alice Walker, *In Search of Our Mothers' Gardens: Womanist Prose* (San Diego: Harcourt Brace Jovanovich, 1983), xi-xii [original emphasis].

ministries of care can learn to value multiple bodily forms and convey that appreciation to others, with and without dis/abilities.

The challenge of loving one's body becomes especially complex when one suddenly finds oneself disabled after years of being a nondisabled person, when there is a discontinuity between the way one's body looked and moved yesterday and the way it looks and moves today. Edie claims that her transition from a nondisabled woman to a woman with a dis/ability was relatively smooth. At first, she thought the effects of her injury were temporary. By the time she realized they were permanent, she had become adept at navigating the world using a wheelchair and comfortable with her body as it now was. Nonetheless, following her injury, Edie reported looking in the mirror and, seeing a young woman in a wheelchair, thinking: "What's she doing there. She doesn't belong there."

For Rebecca, the change in her body was more dramatic and resulted in a sense of disconnection from her body. After she became disabled, she didn't recognize the woman who looked back at her in the mirror. "I didn't know who that person was that I was seeing. And that was scary and really sad." To suddenly not know oneself, to feel utterly disconnected from one's body, to be someone who does not seem to look at all like the person one has been, would be terrifying. Inhabiting, much less loving, a body one does not recognize as one's own is difficult enough without the added devaluation society places on bodies with dis/abilities.

The mirror still is not always a friend, but both Edie and Rebecca sometimes enjoy the woman in the mirror. Edie, when she puts on make-up and fixes her hair, can look in the mirror and be confident she looks pretty. Rebecca finds herself playing in the

mirror. "There are times now, maybe for the last year or two, that I can actually look in the mirror and like what I see, feel like I look pretty. And I can—you know, a lot of people play in mirrors, you make faces at yourself and you strut and you dance—I can do that now." It is not that they enjoy their bodies and declare themselves pretty *despite* dis/ability. These women love themselves and find themselves attractive in the midst of living with dis/ability. This is an act of cultural resistance, and the task of pastoral theologians and persons who offer pastoral care and counseling is to join that resistance.

Some things that happen to the body neither seem nor feel good. Pain, deterioration, and unpredictability of the body present complications to the affirmation that bodies are good. Sometimes it seems as if our bodies turn on us. It is difficult to tolerate, much less like or love, a body that is in pain, attacks itself, or is unpredictable. Joanne's body is often wracked with pain. People with autoimmune diseases, such as multiple sclerosis, know that their body is attacking itself. Some bodies, like the body of Robert Murphy, slowly deteriorate from the toes upward. Murphy talks of feeling increasingly disembodied.[49] Our bodily experiences are varied.

My friend, who is a hospital chaplain and who recently spent the better part of a year caring for her dying mother, argues with me about this concept of bodies being good. She has witnessed bodies deteriorating and bodies working against themselves and bodies in pain. She says such pain and deterioration cannot be compatible with goodness. She wants me to say that bodies are sacred or valuable or should be respected. She objects to my insisting that bodies are good.

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[49] Robert F. Murphy, *The Body Silent* (New York: W.W. Norton, 1990), 100.

Still I want to maintain that, even in the midst of pain and deterioration and part of a body attacking other parts of the same body, bodies are good. Too many acts of harm and brutality have been committed against bodies precisely because they are considered "no good"—problematic, difficult, different—and, therefore, considered appropriate targets for violence—beatings, rape, murder. People with dis/abilities have been "warehoused" because others thought it was the best way to take care of bodies that are not under the control of the person whose body it is. Thus, I want to agree that bodies are sacred and valuable and should be respected—and add, as well, that bodies are "good."

Patricia L. Wismer articulates a feminist theological viewpoint that begins with the diverse experiences of pain in the lives of eight women. She argues that

> having an accurate picture of the basic goodness and worth of our bodies/ourselves is essential to a theological anthropology of pain. . . . [E]mphasizing the basic goodness of bodies and feelings is not to deny the ambiguity that is also part of our bodily experience. . . . The goodness is present but not untouched by tragedy. If we mourn the tragedy, we must also celebrate the goodness.[50]

Bodies are good, valuable, sacred, and demand respect. Bodies can also be unpredictable, deteriorate, and in pain. Neither truth denies the other.

When we focus on what bodies cannot do, we demonstrate a very narrow understanding of the variety and the goodness and the possibilities of bodies. When we ascribe goodness to only certain bodies and deny it to others, we do all bodies a disservice. Affirming the goodness of all bodies is a starting place for communities of faith to move toward a theological foundation that values all persons and that leads to the

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[50] Patricia L. Wismer, "For Women in Pain," in *In the Embrace of God*, ed. Ann O'Hare Graff (Maryknoll, N.Y.: Orbis Books, 1995), 150.

elimination of attitudinal and architectural obstacles, so that all persons have the opportunity to live fully and to fully belong.

Physicality and Representations of Woman and Dis/ability

Consumer culture puts forth a representation of woman, of what women *should* look like, which resembles very few actual women. Yet, it is this prototype to which we in the United States are exposed, and which we inevitably internalize through a process that is largely unconscious. We may eventually consciously choose to imitate or reject certain characteristics of this representation, but we cannot totally divorce ourselves from our own culture's model of woman. Being seen as a representation, whether of woman or dis/ability, results in not being seen as one is. In her study of representations of women, Mulvey refers to "woman's fantasy presence and real absence."[51] Representations of dis/ability produce the same "fantasy" presence of the image and real absence of the person. At the same time, the "fantasy" is very real to those whose restricted vision reconstitutes it with each encounter. In the mind whose eye sees dis/ability or woman and conjures up the cultural representation, the "fantasy" is a real and active presence even though the imagined representation may have little or nothing to do with the real person whom the eye observes.

One of the most valued and desired feature of consumer culture's version of woman is her physical attractiveness. Women are often selected (or eliminated) as partners, companions, friends and workers based solely on their looks. Extremely narrow standards of attractiveness are prescribed for women. These codes of beauty confront us in women's magazines, media commercials, early morning news-entertainment

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[51] Mulvey, 7.

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television, and talk shows. Invitations and exhortations to erase wrinkles, lose weight, firm our bodies, and dress in runway fashions fill our airwaves and beckon us as we wait in the grocery check-out lane. Beauty pageants—Miss America, Miss Universe, Miss World—are another way women and girls, including very young girls who even have contests of their own, are told what we should aspire to be. At the end of the Miss America contest, the host sings, "There she is Miss America, your ideal." One woman with an invisible dis/ability has been selected as Miss America, but it is highly improbable that a woman with a visible physical dis/ability will ever be chosen a representative of the idealized version of woman's outward appearance. Physical dis/ability is not compatible with the ideal physical body.

Everywhere women look, we are told what our bodies should look like—and the goal is perfection. "With created images setting the standards, we are becoming habituated to the glossy and gleaming, the smooth and shining, the ageless and sagless and wrinkleless. We are learning to expect 'perfection' and to find any 'defect' repellant, unacceptable."[52] According to cultural critic Susan Bordo, the current cultural representations homogenize women, "smoothing out all racial, ethnic, and sexual 'differences,'"[53] such as Jewish noses and Asian eyes.[54] Furthermore, these homogenized images present the norm against which society judges women.[55] Worse yet, we are told that the perfect body is achievable and worth it, and reports of the horrors of striving for physical perfection are rare. The woman's body that is "up to par" is the "flawless"

[52] Susan Bordo, *Twilight Zones* (Berkeley: University of California Press, 1997), 3.
[53] Susan Bordo, *Unbearable Weight* (Berkeley: University of California Press, 1993), 24.
[54] Bordo, *Twilight Zones*, 50.
[55] Bordo, *Unbearable Weight*, 25.

body.[56] Women are continually judged—and we judge ourselves—by standards of perfection, which are, by definition, unattainable. This serves to focus our attention on our "flaws," even though no one, not even the most sought after and highly paid models, has this "perfect" body.

Associating women with defective bodies is not a new idea. Aristotle wrote that "the female is . . . a deformed male."[57] According to Christian feminist theologian Rosemary Radford Ruether, Christian theology in the medieval scholastic tradition draws on Aristotle to support

> the basic patriarchal assumption that the male is the normative and representative expression of the human species and the female is not only secondary and auxiliary to the male but lacks full human status in physical strength, moral self-control, and mental capacity.[58]

Looking for the "defects" in women—physically, morally, and mentally—has a long history. Consumerism promotes the continuation of this tradition. Bordo argues that the cosmetic surgery industry contributes to setting the standards for what is acceptable or "defective" in a woman's body.[59]

The representation of woman as requiring the perfect body, even participating in self-surveillance of her body with an eye out for finding every "repellant" defect in order to correct it, is the antithesis of the image of a woman with a dis/ability as "defective." The inability to strive for perfection, and the futility in trying, is a strike against women with dis/abilities. Both the social stigma of dis/ability and the unwomanly defect of having an uncorrectable "imperfection" affect the way others see the woman with a

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[56] Bordo, *Twilight Zones*, 39-40.
[57] Aristotle, *Generation of Animals*, 775a, as cited by Rosemary Radford Ruether, in *Womanguides* (Boston: Beacon Press, 1985), 75.
[58] Ruether, 65.
[59] Bordo, *Twilight Zones*, 42-43.

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dis/ability, and the way she sees herself. It becomes a moral issue. She transgresses the

codes of beauty and the requirement to "improve" herself by eliminating her "flaws."

Attractive people are credited with positive features based solely on their

appearance. They are believed to be "more sensitive, kind, interesting, strong, poised,

modest, sociable, outgoing, and exciting, sexually warm and responsive."[60] The corollary

of this is that the presence of dis/ability is regarded by some as a sign of a character flaw

or punishment for some wrong-doing. Rebecca tells of a time when she was approached

by a man who indicated a desire to pray for her. She said that would be okay. However,

when he reached out his hand to pray for her in the moment, she told him that he could

pray for her at home or at church but not in the middle of the street.

> Then he moves back and he starts pointing at me and . . . talking about how he's
> what I would probably refer to as a holy roller [but] that he's a very adamant
> Christian and he prays all the time. Then he starts telling me that—this is what he
> said exactly—"you are what is prophesied in the book of Revelation that good
> shall turn evil . . . you and your family have sinned and you've sinned for
> generations . . . and that is why you are in that chair—because of your sin!"

Women with dis/abilities may be seen as not only violating codes of beauty but

moral ones as well. A variation on this line of thinking suggests that the presence of

dis/ability indicates a lack of faith. At a conference I attended recently, one of the other

participants, who is blind and a person of faith, told of waiting for the subway to arrive

when someone came up next to her and whispered, "If you truly believed, you'd see by

the time the train comes."

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[60] Adrienne Asch and Michelle Fine, "Introduction: Beyond Pedestals," in *Women with Disabilities: Essays in Psychology, Culture, and Politics*, ed. Michelle Fine and Adrienne Asch (Philadelphia: Temple University Press, 1988), 16, quoting E. Berscheid and E. Walster, "Beauty and the Beast," *Psychology Today*, March 1972, 46.

Elements of Jewish and Christian religious traditions have supported a connection

between visible dis/ability and moral flaw. Avi Rose, who writes on dis/ability and

religion, suggests that the reason "may lie in the ancient belief systems of the Judeo-

Christian theology which views disability in a highly negative manner."[61] The book of

Leviticus contains at least two examples of this view. In Leviticus 21-22, the writer of

the book claims that God gives strict and exact instructions about the offering of

sacrifices. Neither the priest who presents the offering nor the animal which is offered

shall have a physical defect due to a fear that God's holiness would be contaminated by

contact with persons deemed to have "blemishes."[62] Exegetical work on Leviticus 13-14

regarding changes to the surface of the skin shows that "[d]ecisions about physical

purity/impurity have a strong visual basis, and deviations from physical norms may be

interpreted as signs of God's displeasure."[63] However, there are alternative narratives

within the same biblical book. Leviticus also commands the people of God not to be

contemptuous toward the deaf nor obstruct the way of the blind.[64] Turning to the New

Testament, Walter Wink states that Jesus saw holiness in a new light—God's holiness,

rather than being in danger of contamination, is "contagious." That is, it changes those

who come in contact with it, not the other way around.[65]

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[61] Avi Rose, "'Who Causes the Blind to See': Disability and Quality of Religious Life," *Disability and Society* 12, no. 3 (1997): 396.

[62] Lev. 21.17; Lev. 22.20.

[63] Sarah J. Melcher, "Visualizing the Perfect Cult: The Priestly Rationale for Exclusion," in *Human Disability and the Service of God: Reassessing Religious Practice*, ed. Nancy L. Eiesland and Don Saliers (Nashville: Abingdon Press, 1998), 69.

[64] Lev. 19.14.

[65] Walter Wink, "'Holy and without Blemish before God': Disability and Normalcy," in *And Show Steadfast Love: A Theological Look at Grace, Hospitality, Disabilities, and the Church*, ed. Lewis H. Merrick (Louisville: Presbyterian Publishing House, 1993), 76.

Occasionally, dis/ability is viewed as something visited upon someone who is special and, therefore, more able to handle the supposedly enormous, even superhuman, obstacles. This is the "saint" category, the polar opposite of the "sinner" classification. For centuries women have been categorized in binary ways, either "whore" or "madonna," Jezebel" or "mammy."[66] The "saint" label is as inaccurate a representation of dis/ability as the category "madonna" or "mammy" is of a woman. Nonetheless, it is a category in which women with dis/abilities are sometimes cast. Interestingly, the same woman may be viewed as both "sinner" or "saint" depending on the observer. Remembering Rebecca's story of being accosted on a city street and told she was in a chair because she and her family had sinned, Rebecca also encountered religious responses categorizing her as a saint.

> The other religious response I get is of people staring at me because they think I'm so amazing. (She laughs.) They want to put their hands on my shoulders or on my head or pat my back. Sometimes they want to grasp my hand. Then they talk about how they see God in me or—I had one woman tell me that I was proof that prayers work.

She finds these comments "bizarre" and unwelcome. She tends to make fun of this perspective.

> It's really a strange phenomenon and I do think I have to laugh about it and talk about it just to deal with it. I think if I were really to take it seriously, a) I would have a really huge ego, and b) I would—what would I do? If I'm God's representative on earth and God's doing all these things through me, how do you live your life? So I do make light of them and I certainly would never advertise myself as being any of those things.

Both the "saint" and the "sinner" categories view people with dis/abilities through a one-dimensional frame. Neither adequately recognizes the person as she is.

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[66] See Delores Williams, *Sisters in the Wilderness* (Maryknoll, N.Y.: Orbis Books, 1993), 70-71, for a brief discussion of common negative images of black women.

Representations of women with dis/abilities often image them as needy, dependent, and without much to offer—the prototypical invalid waiting for the charity of another. However, the assumption that dis/ability and need go hand in hand and take priority in the lives of women with dis/abilities is a false assumption. Adrienne Asch, a professor at Wellesley College and noted dis/ability studies scholar, who also happens to be blind, describes an exchange that illustrates both the assumption of neediness of women with dis/abilities and her reaction to it.

> Sitting beside a stranger waiting for a lecture to begin at an academic conference, the stranger whispers loudly not "Hello, my name is Carol," but "Let me know how I can help you." What help do I need while waiting for the speaker to begin? Why not introduce herself, rather than assume that the only sociability I could possibly want is her help?[67]

As with nondisabled persons, there are times when a person with a dis/ability does need and appreciate assistance, but that is not always, or even most often, the case. Asch responded "by saying that she can let me know if I can help her."[68]

Representations of people with dis/abilities as primarily being in need of the charity of others is not without consequences. Rose identifies two problems. First, the person with a dis/ability is objectified and becomes "a project, a vehicle for others to fulfill their acts of kindness."[69] As noted in chapter 3, Liz reported strangers throwing money at her. When a woman with a dis/ability is a "project," she is not seen as an individual in her own right but as a "cause"—the recipient of another's activity. A popular proverb claims that "it is more blessed to give than to receive." The tendency to place giver and receiver in a hierarchical relationship diminishes the goodness of the one

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[67] Adrienne Asch, "Critical Race Theory, Feminism, and Disability," *Ohio State Law Journal* 62, no. 1 [journal online]; accessed 1/15/02; available from http://www.osu.edu/units/law/LawJournal/asch.htm.
[68] Asch, "Critical Race Theory."
[69] Rose, 399.

who gladly receives needed and desired assistance. It is equally blessed to willingly benefit from another's gift and to have the resources—physical, spiritual, emotional, or financial—to give. It is essential to preserve the righteousness of both giver and receiver.

Second, Rose points out that the needs of persons with dis/abilities "are not necessarily seen as rights, but as privileges of a society that can afford to care for them."[70] Therefore, in times of plenty, generosity toward persons with dis/abilities, and others, is allowed, even encouraged. But, in times of want, when budgets of civil or charitable agencies need to be cut, services are viewed as expendable. That the needs of those who receive do not take priority is true in individual as well as organizational relationships. For example, Joanne tells of being at a gathering without her usual chair, which she can control herself, and using a chair that needed to be pushed. Someone kindly volunteered to push her chair. However, the volunteer took her with him as he visited the people he wanted to see. She, therefore, missed spending time moving about and talking to persons she had looked forward to seeing.

Representations of woman and dis/ability overlap and diverge. Both women and people with dis/abilities have been called defective and deformed. Both have been labeled dependent and needy.[71] The needs and desires of persons from both groups have been secondary when others are in positions of power. Both have been used to symbolize sinfulness. The meshing of representations reinforces the negative images of persons who are both woman and have a dis/ability.

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[70] Rose, 399.
[71] A nondisabled woman doing research in the field of dis/ability studies was once asked, "Why study women with disabilities? They reinforce traditional stereotypes of women being dependent, passive, and needy." Asch and Fine, 4.

Nonetheless, an area of divergence, which surrounds the matter of appearance, is especially damaging. The standards of physical beauty for women in consumer and popular cultures and the negative judgments against persons who deviate from those standards have an impact on the lives of women with visible dis/abilities. Public policy and dis/abilities studies scholar Harlan Hahn finds a relationship between discrimination against people with dis/abilities and "aesthetic anxiety," which he describes as

> fears engendered by persons whose appearance deviates markedly from the usual human form or includes physical traits regarded as unappealing. These fears are reflected in both the propensity to shun those with unattractive bodily attributes and the extraordinary stress that modern society devotes to its quest for supernormal standards of bodily perfection.[72]

Having a dis/ability has a greater effect culturally on women than on men, because women are more likely than men to be judged, at least in part, based on their appearance. Fewer social, educational, and employment opportunities are available to women with dis/abilities than to men with dis/abilities.[73] Women with dis/abilities are less likely than either nondisabled women or men with dis/abilities to marry, be living with a partner, or have children.[74] Women with dis/abilities are more likely to have less formal education than the other two groups and less likely to be employed, compared to others at the same educational level.[75]

These gaps cannot be explained by the two factors of discrimination against women and people with dis/abilities. Researchers William John Hanna and Betsy Rogovsky, who compared women with dis/abilities with nondisabled men, nondisabled

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[72] Harlan Hahn, "The Politics of Physical Differences: Disability and Discrimination," *Journal of Social Issues* 44, no. 1 (1988): 42.

[73] William John Hanna and Betsy Rogovsky, "Women with Disabilities: Two Handicaps Plus," *Disability, Handicap and Society* 6, no. 1 (1991): 49-63.

[74] Hanna and Rogovsky, 52.

[75] Hanna and Rogovsky, 52-53.

women, and men with dis/abilities relative to multiple socio-economic categories,

discovered disproportionate ratios that signaled to them a "plus" factor.[76] If adjusting for

gender and dis/ability do not account for the ratios, then a third factor must be at work,

which they describe as the combination of women and dis/ability.

> To explore why disabled women are apparently more stigmatized than disabled
> men—even more than sexism and able-ism would lead one to predict—we turn to
> the female/disabled 'plus factor.' We suggest that three elements may be
> involved: the social inappropriateness of the disability's cause [i.e., the belief that
> women bear some responsibility for their dis/ability], impaired nurturance, and
> despoiled beauty."[77]

If their analysis is accurate, appearance ("despoiled beauty") is one of three factors that

lead to multiple and wide-ranging negative social and economic consequences for women

with dis/abilities.

Some of the themes in this chapter find their way in a slightly different form into

chapter 5, in which I argue that the oppressive gaze is, in several ways, annihilating. An

emphasis on "normal" is connected to methods of annihilating persons whose bodies do

not fit the "normal" category. A failure to identify all bodies as good leads to the

annihilation of the value of some bodies. The inability to resolve conflicting

representations of "woman" and "dis/ability" results in "disability" overshadowing or

erasing "woman." In each of these areas, women with dis/abilities resist annihilation by

claiming for themselves the very characteristics that society, with its limited vision and

restricted narratives, is unable to see.

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[76] Hanna and Rogovsky, 54.
[77] Hanna and Rogovsky, 54.

CHAPTER 5

DIS/ABILITY, ANNIHILATIONS, AND RESISTANCE

Viewing another with a very narrow focus and distorting lens is annihilating. That is, it reduces a person to nothingness or nonexistence; it obliterates features unnoticed. This act destroys the wholeness of the person and constructs her into a fraction of what she is. Such restricted perception may result in multiple annihilations for women with dis/abilities. I use the plural, annihilations, both because of the multiple forms of annihilation and because it can happen again and again.

This chapter focuses on the consequences of a stare that (re)creates one-dimensional representations of dis/ability. This chapter consists of six sections—three discuss forms of annihilation toward people with dis/abilities, three contain alternative narratives that highlight resistance to annihilating circumstances. The first section, "Annihilation: Better Dead Than Disabled," deals with literal, physical annihilation. The second section, "Resistance: 'Not Dead Yet,'" argues that life with a dis/ability, though it may be difficult and unpredictable at times, is a life worth living. The third section, "Annihilation: Not Quite Human," describes the annihilation of human value of persons with dis/abilities. In the fourth section, "Resistance: 'I'm God's Servant,'" people with dis/abilities challenge dominant narratives by claiming their inherent value as a human being. The fifth section, "Annihilation: Not Even a Woman," illustrates how dis/ability as a "master category" annihilates gender. The final section, "Resistance: 'I know I Look Fine,'" counters that women with dis/abilities view themselves and are viewed by others as attractive and capable people.

Annihilation: "Better Dead Than Disabled"

People with dis/abilities have been subject to literal annihilation—physical

death—for the simple reason that their bodies are considered "disabled." Arguments for

selective abortion, withholding of medical treatment, assisted suicide, and "mercy"

killing frequently center on issues of dis/ability. In his review of images of people with

dis/abilities in television and movies, Paul K. Longmore, a historian and dis/ability

scholar, explains that one of the dominant messages about dis/ability is that "disability

makes membership in the community and meaningful life itself impossible, and death is

preferable. Better dead than disabled."[1]

Gene altering, embryo testing, selective abortion, and permitting people (adults,

children, and infants) to die even when medical help is available are not simple issues.

They often require family members and medical professionals to make complex and

difficult ethical decisions and to make them quickly. Such complexities demand a

careful, case by case examination of the many facets of the situation from various

vantage points. When membership in a stigmatized group, and not a full exploration of

the case, drives decision-making, discrimination exists. In other words, if the mere

presence of dis/ability determines a course of medical treatment different from, and less

aggressive than, what would be followed in the case of nondisabled persons, the cultural

message, "better dead than disabled," is at work.

One traditional argument put forth to justify continued legalization of abortion is

to prevent a child with dis/abilities from being born.[2] Often couched in phrases such as

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[1] Paul K. Longmore, "Screening Stereotypes: Images of Disabled People in Television and Motion Pictures," in *Images of the Disabled, Disabling Images*, ed. Alan Gartner and Tom Joe (New York: Praeger, 1987), 70.

[2] Jenny Morris, *Pride Against Prejudice* (Philadelphia: New Society Publishers, 1991), 64.

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"not wanting to bring into the world a child who would be a burden to family and society," it makes the assumption that the presence of dis/ability in a family member inevitably means a hardship, nothing but a hardship, and more hardships than those associated with nondisabled family members. Genetic testing can now determine whether or not a prospective parent is a carrier for some hereditary conditions and whether or not an embryo will develop that condition. Medical procedures, such as amniocentesis, can also discover if a fetus carries a particular trait and will or will not be born with a certain dis/ability. Both genetic testing and amniocentesis provide medical justification for aborting fetuses with dis/abilities.

A fetus who has a dis/ability is considered to be in a different category from those presumed to be nondisabled fetuses. One marker for disallowing an abortion to be performed is the fetus' viability outside the mother's body, generally established at 20-24 weeks gestation. State laws may prohibit postviability abortions, with one exception—if the pregnancy poses a danger to the mother's life or health. A "fetal deformity and abnormality . . . [is] one aspect of a pregnant woman's physical and mental health."[3]

Recently, another example of the "better dead than disabled" message has entered the scene. In France, at least two cases have come before the courts in the past several years contending "wrongful *birth*." The parents of children born with dis/abilities argued that the doctors were negligent because they had failed to warn the parents that a dis/ability in the fetus was either likely or evident. In one case, the mother had contracted "German" measles during her pregnancy, and in the other, prenatal screening showed

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[3] "Late-Term Abortions: Legal Considerations," *Issues in Brief*, (Alan Guttmacher Institute, January 1997), online, accessed 13 Mar. 2004; available from http://www.guttmacher.org/pubs/ib13.html. In Great Britain, pregnancies may be terminated after 24 weeks if there is evidence that the fetus would have a dis/ability. Morris, 67.

symptoms of a dis/ability in the fetus. The parents argued that, had they known that the children were likely to be born with dis/abilities, they would have aborted the fetuses. The courts agreed with the parents—the children should not have been born.[4]

The idea that life with a dis/ability is a life not worth living shows up in the hospital nursery. One example is Baby Jane Doe from Long Island, who was born with spina bifida and hydrocephalus in 1983. She came to the attention of the media which reported grim facts about her future life, although other available information that could have modified the dismal reports was rarely included.[5] Her parents, with their obstetrician's counsel, initially decided to go the route of non-intervention, thus preventing surgeries that could help her.[6] According to hospital officials, survival was unlikely without the operations.[7] The courts did not prosecute the parents.[8] Months later, the parents allowed some medical treatments to be performed.[9]

Baby Jane Doe is not alone. Some newborns do indeed have conditions that are untreatable and terminal, and using heroic measures to prolong the dying process would be cruel and unjust. However, other babies have dis/abilities that are stable or, as in the case of spina bifida, conditions for which early treatment can minimize the disabling effects.[10]

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[4] Nanette van der Laan, "France Debates Right Not To Be Born," *Christian Science Monitor* Dec. 7, 2001 [online newspaper]; accessed 9 Dec. 2001; available from http://www.csmonitor.com/2001/1207/pls3-woeu.him.

[5] Douglas Biklen, "Framed: Print Journalism's Treatment of Disability Issues," in *Images of the Disabled, Disabling Images*, ed. Alan Gartner and Tom Joe (New York: Praeger, 1987), 84-85.

[6] Nat Hentoff, "The Awful Privacy of Baby Doe," in *Images of the Disabled, Disabling Images*, ed. Alan Gartner and Tom Joe (New York: Praeger, 1987), 171.

[7] Biklen, 80.

[8] Hentoff, 166. Child protection laws were amended and are now used to reduce the occurrence of nontreatment, 176.

[9] Hentoff, 171.

[10] Hentoff, 162-63.

Critics of the media blame biased reporting on the habit of presenting stories about dis/ability in patterned ways. "Disability, for example, is typically cast in terms of tragedy, of charity and its attendant emotion, pity, or of struggle and accomplishment."[11] When the public judges certain lives as not worth living, the media has little incentive to change its habits. Similarly, when the media portray certain lives as either pitiful or unusually courageous, the public's simplistic and stereotypical assumptions about living with a dis/ability remain undisputed.

In the aftermath of coverage in the popular press of a report on death as a "management option" for infants with dis/abilities, counseling psychologist Sondra Diamond, a woman with severe dis/abilities, wrote to a weekly magazine that covered the story to share her thoughts on the topic. Her parents were also told at her birth that she had little chance for quality of life. When she was in her twenties and hospitalized for burns, physicians were not eager to treat her because of her dis/ability. Her parents insisted. Though she indicates that she needs help with basic life tasks, she states that she would not give up a minute of life.

She suggests that "[i]nstead of changing the law to make it legal to weed out us 'vegetables' [a word the magazine used in a previous issue to designate infants with severe dis/abilities], let us change the laws so that we may receive quality medical care, education, and freedom to live as full and productive lives as our potentials allow."[12] The lack of sufficient care options for persons who require assistance with the tasks of daily living does not seem to be one of the health care issues the media or politicians have chosen to accentuate.

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[11] Biklen, 81.

[12] As quoted in Hentoff, 168. No citation given.

Persons who support assisted suicide disregard the care issues of dis/ability and assert that certain lives are simply not worth living. Those lives are often people with terminal illnesses or dis/abilities. The case of Elizabeth Bouvia, a woman with cerebral palsy, raises several important points. Historian Longmore writes about her.

> A 26-year-old woman, attractive and educated, checks herself into a hospital psychiatric unit announcing her wish to commit suicide. She reports that she has undergone two years of devastating emotional crises: the death of a brother, serious financial distress, withdrawal from graduate school because of discrimination, pregnancy and miscarriage and, most recently, the breakup of her marriage.
> She also has a serious physical disability, which she says is the reason she wants to die.
> Three psychiatric professionals ignore the series of emotional blows, concluding that she is mentally competent and that her decision for death is reasonable. They base their judgement on one fact alone—her physical handicap.[13]

The judge who heard the case decided that, because of her immobility and reliance on others for her care, such release from "suffering" was rational.[14] Nondisabled people tend to imagine that, if they were in a situation where they became disabled, they would not want to live. Even people with dis/abilities sometimes think that if their particular dis/abilities were "worse," they would not want to live. Nancy Mairs, who has progressive multiple sclerosis, writes about attending a conference and sitting at lunch near a man with MS who had the same relatively mild symptoms she had had several years earlier. During the luncheon, she remembered a time when her symptoms were mild and recalled thinking, as she looked around the room at folks in wheelchairs, that she would not be able to bear it if her disease progressed to that stage. Yet, time had passed, and there she was, sitting in a wheelchair and bearing it quite well.

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[13] Paul Longmore, "Whose Life Is This, Anyway?" in *Spinal Network*, ed. Sam Maddox (Colorado: Spinal Network and Sam Maddox, 1987) 195, as quoted in Morris, 39.

[14] Longmore, as cited in Morris, 39.

I remembered looking like him. . . . At the time, I tended to avoid gatherings of people with MS, but when I did see people hunched in wheelchairs or scooters, listened to their slurred speech, watched them fumble their coffee cups and forks, my response was clear and adamant: "Oh, no. I can bear the way I am right now, but I could never stand being like that. This far I can go, but no further."

"I was like you once," I said aloud now, turning toward [him], "and I thought then that I couldn't stand being the way I am now. . . . And now I am the woman I thought I could never bear to be." Just then the conference leader caught my eye, and I pulled away from the table and got ready to roll up onto the stage and read [my essay].[15]

In the essay, Mairs declares, *"This is my life. . . . And I'd better get on with it because it matters."*[16]

Living with a dis/ability, though sometimes very difficult, is not generally the unbearable situation others may think it is. Having access to adequate care and appropriate resources can make the difficulties of the situation manageable. Perhaps what Bouvia needed was better support. She is quoted as saying, "I'm not eating because I wish to die. . . . People are saying I've given up hope. That's not it. I'm just being realistic. I had high ideals. I thought I could succeed. But little by little I realized that supporting myself and living an independent life is an impossibility. Now I know what it will take. I'm more realistic."[17]

Her dreams of supporting herself and living independently did not work out. She had trouble finding qualified and reliable personal assistants and was unable to manage without them.[18] Trying to live without aides or with constantly revolving ones was another dimension of stress added to the losses she already experienced. "The disability movement argues that society should make adequate resources available for those whose

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[15] Nancy Mairs, *Carnal Acts* (Boston: Beacon Press, 1996), 16.
[16] Mairs, *Carnal Acts*, 146.
[17] Quoted in Biklen, 80.
[18] Biklen, 86.

physical and intellectual differences mean that they have particular needs. In so doing, we maintain that this is our right as citizens and that a society which seeks to be humane and just should recognise and celebrate diversity."[19]

"Mercy" killing is another way society plays out the belief that certain lives are not worth living. In Canada in 1993, Tracy Latimer's father killed her by carbon monoxide poisoning. Tracy was a 12-year-old girl with a severe dis/ability. She was reportedly in pain, which her father confessed to have found intolerable, but surgery to alleviate the pain was 18 days away. In addition, her father is also alleged to have said that she was in no distress the morning he murdered her.

The circumstances surrounding Tracy's death have become a rallying cry for Canadians with dis/abilities. Their reaction was sparked not only by the killing of a person with dis/abilities, but also because of the public's overwhelming sympathy for the father. Dick Sobsey, a violence and disability researcher states that, "Tracy's media identity as 'damaged goods' allowed the public to dismiss the crime against her. A crime committed against a 'nonperson' is not considered a crime. Creating this image was not difficult since society already has learned much of this bias against people with disabilities."[20] Sobsey puts the public support of Tracy's father in sharp contrast to the public's outrage against Susan Smith, a South Carolina parent who killed her two young sons. Two major differences between these cases are dis/ability and the gender of both the perpetrators and victims. The public was understanding toward a man killing his

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[19] Morris, 78-79.

[20] Dick Sobsey, "The Media and Robert Latimer," online, accessed 3 Sept. 2001; available from http://www.pcs.mb/~ccd/ch7.html.

disabled daughter but unforgiving toward a woman causing the death of her two nondisabled sons.

When society views particular lives as not worth living, murder is justified as "mercy" killing. The Nazis, for example, first tested their eugenics policies on children with dis/abilities. It was done in a very orderly fashion with the assistance of physicians and midwives who were asked to register young children in their care if the children had dis/abilities. A committee of physicians then decided which children would live and which would die on the basis of the forms submitted. The children selected for elimination were gathered in special institutions in order, parents were informed, to give better treatment. Some children were starved, some died of exposure from buildings without heat, some from injections. When the systematic murder of this group of people proceeded without opposition, adults with dis/abilities (except war heroes) were added to the list, and then others.[21]

Susan Wendell connects Western society's eugenics efforts with perfectionist standards and the conviction that certain people can decide what is best for other people.

> The desire for perfection and control of the body, or for the elimination of differences that are feared, poorly understood, and widely considered to be marks of inferiority, easily masquerades as the compassionate desire to prevent or stop suffering. It is not only a matter of being deceived by others, but all too often a matter of deceiving ourselves. It is easy to make the leaps from imagining that I would not want to live in certain circumstances to believing that no one would want to live in those circumstances, to deciding to prevent people from being born into those circumstances, to supporting proposals 'mercifully' to kill people living in those circumstances—*all without ever consulting anyone who knows life in those circumstances from experience.*[22]

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[21] Morris, 50-54, citing Robert N. Proctor, *Racial Hygiene: Medicine Under the Nazis* (Cambridge: Harvard University Press, 1988), 186-87.

[22] Susan Wendell, *The Rejected Body* (New York: Routledge, 1996), 156 [emphasis added].

The cultural diminishment of a group of people can lead to other persons (with presumed superior knowledge) taking active measures to end a life or preventing the enacting of measures to promote life.

Of course, not every person with a dis/ability is, has been, or will be subject to the threat of abortion, withholding treatment, assisted suicide, or "mercy" killing. However, if physical annihilation happens for some, the threat of or extreme vulnerability to violence exists on some psychological level in the inability to meet society's standards of perfection and control, in the distance that separates people and ranks them according to their physical appearance, and in the idea that it is okay for some people to make decisions for others without their input or the input of others with similar dis/abilities.

Resistance: "Not Dead Yet"

An activist group within the dis/ability rights movement calls themselves Not Dead Yet.[23] This name highlights the cultural view that people with dis/abilities are believed to be "better off dead." It also declares that people with dis/abilities are very much alive and most believe their lives are worthwhile. Not Dead Yet challenges the notion that people with dis/abilities will be passive and put up with disregard. Rather it suggests that one's basic approach is toward life, toward the affirmation of life, and that one has the intention of moving toward that which is life-giving.

Such affirmations belong not just to secular advocacy groups but to the heart of a Christian pastoral theology based in ministries of care. It is the Sacred One who breathes life into the human, whose sharp-tongued prophets call the people toward that which is life-giving and warn them of death-dealing ways, and who, in the Christ figure, welcomes

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[23] For more information, see http://www.notdeadyet.org.

those dismissed and discounted by church and society into community and chastises the excluders. The task and call of pastoral theologians and those who offer pastoral care and counseling is to recognize, encourage, and support the essential movement toward life of people with dis/abilities.

The desire for life and for what sustains life is strong. Some circumstances in life interfere with that movement toward life, but living with dis/ability is generally not one of them. The women who shared some of the stories of their lives with me, and others whom I have gotten to know through their writings or in personal conversation, are deeply engaged in life. As with the public in general, there are times when depression sets in and, sometimes, very severe depression. However, most people with dis/abilities most of the time affirm an enthusiasm for life and for the tasks and goals which shape their daily activities. Each one is inclined to move toward that which is life-giving rather than that which is diminishing, demeaning, or destructive of life. Goals of ministries of care include the elimination of practices that conform to deadly cultural messages about dis/ability and nurturance of life-affirming practices in communities of faith. A first step toward eliminating these practices requires sifting out cultural messages in our own heads, and helping others to do the same, that suggest that certain lives are not worth living or that certain circumstances make quality of life impossible.

To affirm life and encourage just relationships does not mean ignoring difficulties. One can affirm that life is good and hold on to what is life-giving without denying what is painful or challenging. One of the women I interviewed reported that there are times when the loneliness, isolation, and physical pain are unbearable. She concludes in those moments that life is not worth living. She struggles with suicidal

thoughts. But there are other times when her pain is under control, when she is able to get out, be with people, and be engaged in life. Then life is good.

Nancy Mairs, who has lived with depression all of her adult life and who has multiple sclerosis, considered at one point whether or not to end her life while she had the strength to do so. She decided against that, concluding that the Nancy she will be then, when the disease has progressed to a state of incapacitation, may well find life meaningful, and the Nancy she is now should not make a decision that the Nancy she will be might not have made at all.[24]

When all is said and done, when the difficulties are counted and the pain and hurt weighed, the joy of and urge for life are usually greater. Such an affirmation of life is foundational for the ability to resist cultural devaluation and annihilation. Resistance is an appropriate response to people and systems that interfere with persons living into the fullness of life. Many women and men with dis/abilities are active in the work of resistance to architectural and attitudinal barriers in church and society. Resistance involves acting out of an affirmation of the value of lives lived with dis/abilities. Resistance involves the (re)creation of communities of faith in which everybody, with whatever limitations and abilities, has a place, where all people experience a sense of belonging. This work belongs to all, and pastoral caregivers who value the well-being and wholeness of each person are called not just to practice inclusion but to join the resistance.

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[24] Nancy Mairs, "On Being a Cripple, in *Plaintext* (Tucson: University of Arizona Press, 1986), 18.

Annihilation: Not Quite Human

Women with dis/abilities face annihilations as human beings of value because of their bodily configuration. As noted in Chapter 2, classical Christian theological formulations have contributed to the devaluation of people with dis/abilities. In traditional theology, the place we meet dis/ability is when addressing the question of theodicy—often stated as a variation of, "If God is all good and all powerful, why does evil exist?" For example, Reformed theologian Shirley Guthrie introduces the problem of natural evil by referring not only to devastating storms, hunger, and disease but also to "a hopelessly deformed physically or mentally" newborn.[25] David Pailin notes that one reason historically given for the appearance of dis/ability in the world is as punishment for sinful behavior.[26] Some people view dis/ability as a sign of a lack of faith, as in the situation mentioned previously where a person approached a woman who is blind as she waited for a train and whispered, "If you truly believed, you'd see by the time the train comes." Linking dis/ability with evil, sinfulness, or lack of faith compromises the value of a person with a dis/ability.

Persons with atypical bodies are devalued and even seen as "not quite human."[27] Thus, the stage is set for denigration of the bodies of women with visible physical dis/abilities through mistreatment (for example, dehumanization, physical abuse, and sexual violence) and medical treatment (attempting to make bodies more like the norm).

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[25] Shirley C. Guthrie, Jr., *Christian Doctrine* (Atlanta: John Knox Press, 1968), 172. Chapter 9, "'Why Doesn't God Do Something About It?': The Doctrine of Providence and the Problem of Evil," addresses the assumption that if God is all good and all powerful, then evil should not exist.

[26] David A. Pailin, *A Gentle Touch* (London: SPCK, 1992), 77-79. He also includes tests of character, 79-80, and opportunities for development, 80-81, as traditional explanations for dis/ability. He, then, critiques each of these reasons.

[27] Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity* (Englewood Cliffs, N.J.: Prentice-Hall, 1963), 5.

Joanne's story demonstrates the dehumanization that can occur in everyday activities. "In the supermarket, before we had ATM cards, we would need to write checks and the people in back of me would say, 'What's taking you so long?' or 'What's wrong with you?' or "Why do you write like that?' It would always be embarrassing to go up there and just start to write [because of] some of the things they would say to me." Many people lack tolerance for different ways of doing things, such as a hand which writes more slowly than the "average" person. Joanne blames it on the impatience of so many folks. Essayist and poet Eli Clare, who also has cerebral palsy, notes the same phenomenon.

> I write slowly enough that cashiers get impatient as I sign my name to checks, stop talking to me, turn to my companions, hand them my receipts. I have failed timed tests, important tests, because teachers wouldn't allow me extra time to finish the sheer physical act of writing, wouldn't allow me to use a typewriter. I have been turned away from jobs because my potential employer believed my slow, slurred speech meant I was stupid. Everywhere I go people stare at me, in restaurants as I eat, in grocery stores as I fish coins out of my pocket to pay the cashier, in parks as I play with my dog. I am not asking for pity. I am telling you about disability.[28]

Failure to ascribe value to women with bodily differences is a form of annihilation.

Clare recalls dehumanizing scenes from her childhood when she was wounded by the painful words spoken or shouted by others.

> Still [after scoring well on an IQ test] I was *retard, monkey, defect* on the playground, in the streets, those words hurled at my body, accompanied by rocks and rubber erasers. Even at home, I heard their echoes. My father told me more than once to stop walking like a *monkey*. My mother often talked about my birth *defect*. Words bruise a body more easily than rocks and rubber erasers.[29]

Clare's particular bodily configuration and speech patterns led to a delay in recognizing her intellectual capacities, the questioning of her humanness, and frequent reminders that

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[28] Eli Clare, *Exile and Pride* (Cambridge, Mass.: South End Press, 1999), 6.
[29] Clare, 68.

her human variation was experienced by others as defective, rather than just different. To be labeled as having characteristics of a primate puts a person in a non-human or subhuman category. Intentionally insulting a person by name-calling or labeling is an affront to that person. To call a person "retard" as an insult is also an extreme disregard for people with cognitive dis/abilities. Furthermore, it sets up an atmosphere of animosity between groups of persons with varying dis/abilities. Clare, for example, refused to be associated with the children in special education.[30] She needed to separate herself from all others who had labels that the nondisabled kids threw at her.

The nondisabled public tends to universalize dis/ability, associating a limitation in one area of the body with the whole body, and a difference, along with the accompanying devaluation, in one person to the whole family. Anthropologists refer to this phenomenon as "spread"—a dis/ability in one area is imagined as dysfunction in multiple areas. Difference spreads to those who are associated with that person, such as family and friends. Thus, it is not unusual for family members, like Clare's parents, to be "deeply ashamed of my cerebral palsy and desperately want[ing] to find a cure."[31] Children and adults with dis/abilities are often in and out of doctor's offices, hospitals, physical therapy departments, faith healers, massage therapists, practitioners of alternative medicine, and so on, searching not only for treatment but also for solutions and, therefore, normalcy.

Seeing certain individuals as "not quite human" leads to disrespect, and disrespect can lead to disinterest and abuse. People who are thought to be not quite or not fully human can be institutionalized at a young age, segregated in nursing homes, prevented

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[30] Clare, 68.
[31] Clare, 69.

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from getting jobs and/or an education, excluded from church communities, and abused

physically, verbally and sexually. In fact, according to Dick Sobsey, people with

dis/abilities are 50% more likely than the nondisabled population to be abused.[32] Two of

the five women I interviewed had been abused, one through sexual abused in childhood,

the other through an abusive relationship in adulthood. We can hypothesize possible

reasons for the increased potential of abuse. People with dis/abilities may be less able to

defend themselves. A person about to commit a random assault is more likely to choose

as a victim the person they consider to be most vulnerable. Some persons with

dis/abilities may not have the capacity to communicate about the assault and, thus, not be

able to report it. Others may not report, because they suspect they will not be believed.

If a caregiver or family member is the perpetrator, a person may be hesitant to complain

for fear of further violence or increased lack of care. Sometimes people with dis/abilities

have fewer options in friends or partners and, thus, accept the risk of abuse in order to

receive some companionship.

Several years ago, a Philadelphia bus driver was convicted of driving a passenger,

a woman with dis/abilities, into a wooded area and sexually assaulting her. The woman,

the news article reported, "has difficulty moving her extremities and speaking." Perhaps

this is what led the judge to say as he sentenced her assailant that "she was not the perfect

victim. She did complain." The woman, who "complained" by reporting the assault,

responded to the conviction and sentence, saying, "Never, never underestimate the

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[32] Wendell, chap. 3, 186, fn 6.

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disabled."[33] Not all women with dis/abilities can complain. At one time forced

sterilization was a common practice for women who were institutionalized and for

persons with dis/abilities that society decided should not be passed on to the next

generation.[34] Sterilization of women in institutions may have prevented pregnancy, but

not sexual assault.

While medical treatment can be a blessing, it can also be another form of

annihilation of the wholeness of the person when it classifies the body as deficient and

seeks to change it. Such medical intervention fails to recognize the body as having an

integrity of its own and attempts to correct dis/abilities for the main purpose of looking

more "normal." Born without limbs, Diane DeVries was fitted continually throughout

her childhood for upper limb prostheses, often with results unsatisfactory to her. The

clinical goals for DeVries were to "normalize" her life. In reality, DeVries experienced

more control over objects if she used her stumps to manipulate and maneuver them.[35]

Sucheng Chan, who had polio at the age of four, discovered the complexity of the issues

surrounding form and function.

> Between the ages of eight and eighteen, I walked without using crutches or braces
> but the effort caused my right leg to become badly misaligned. Soon after I came
> to the United States, I had a series of operations to straighten out the bones of my
> right leg; afterwards though my leg looked straighter and presumably better, I
> could no longer walk on my own.[36]

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[33] Stephanie Doster, "Driver Gets 20-40 Years for a Rape," *The Inquirer* 1 Sept. 2001 [online newspaper]; accessed 3 Sept. 2001; available from http://inq.philly.com/content/inquirer/2001/09/01/local_news/SDRIVE01.htm.

[34] Michelle Fine and Adrienne Asch, "Beyond Pedestals, in *Women with Disabilities*, ed. Michelle Fine and Adrienne Asch (Philadelphia: Temple University Press, 1988), 21 and 22; Marks, 35.

[35] Geyla Frank, "On Embodiment," in *Women with Disabilities*, ed. Michelle Fine and Adrienne Asch (Philadelphia: Temple University Press, 1988), 52-53.

[36] Sucheng Chan, "You're Short, Besides!" in *Making Face, Making Soul=Haciendo Caras: Creative and Critical Perspectives by Feminists of Color*, ed. Gloria Anzaldua (San Francisco: Aunt Lute Foundation Books, 1990), 166.

The cost of "normalizing" appearance may include reducing function. Sometimes the basic integrity of women's bodies, though varying from cultural standards, is best left alone.

Audre Lorde experienced society's disvaluing and disapproval of her bodily difference in a doctor's office following surgery for breast cancer. During her hospital stay she had been visited by a cancer survivor who had encouraged her to get back to "normal" by means of a breast prosthesis. Lorde's concerns were not cosmetic, and she did not use the temporary prosthesis the woman left with her. Having matching breasts was not a very significant part of her self-image. Lorde recalls her experience of leaving her house for the first time after surgery.

> Ten days after having my breast removed, I went to my doctor's office to have the stitches taken out. This was my first journey out since coming home from the hospital and I was truly looking forward to it. A friend had washed my hair for me and it was black and shining, with my new gray hairs glistening in the sun. Color was starting to come back into my face and around my eyes. I wore the most opalescent of my moonstones, and a single floating bird dangling from my right ear in the name of grand asymmetry. With an African kentecloth tunic and new leather boots, I knew I looked fine with that brave new-born security of a beautiful woman having come through a very hard time and being very glad to be alive.[37]

This is not a woman insecure about how she looks or feels. If anything, she is energized by the confidence of knowing she looks as good as she feels. Unfortunately, not everyone shared her opinion. When she arrived at her destination, the usually supportive nurse chided her for appearing without wearing the prosthesis she had been given because "it's bad for the morale of the office."[38] Society's emphasis on a typical bodily

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[37] Audre Lorde, *The Cancer Journals*, 2nd ed. (San Francisco: Aunt Lute Books, 1980), 58.
[38] Lorde, 59.

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form—in this case, achieving symmetry—is so strong that one's personal sense of well-being is discounted.

Resistance: "I'm God's Servant"

As Audre Lorde demonstrated in the story above, one's life and one's body—as it is—are more valuable than conventional appearance. Lorde was much more concerned about the threat that cancer posed than with pretending one breast was not amputated. She wrote an alternative narratives in which asymmetry was part of being a beautiful woman who celebrated being alive.

Joanne makes a most revelatory statement about the difference between living harmful dominant narratives and the power of alternative narratives when she mentions her move from a "regular" school, where she was subject to abuse, to a school for children with dis/abilities. "When I started going there [the school for children with dis/abilities], my life really changed. People actually liked me and talked to me." Being liked by others comes as a surprise when home life is "dysfunctional" due to alcoholic and abusive parents, and the atmosphere in the "regular" school involves "getting either thrown down the stairs or beaten up."

The church provided a safe place for her in those days, a place where she could "hid[e] out, like if my Mom was on a rampage." Joanne is well-connected to the people in her denomination. She participates in the installation of bishops and provides leadership to women's organizations within her denomination. The day I visited with her, she was preparing a birthday surprise for the church secretary.

Though many of her experiences with the church are affirming, it was in the face of disvaluing experiences at church that Joanne wrote a poem asserting her worth as a

human being. "I wrote that poem out of a lot of hurt one day. I don't go to the parish hall anymore after church, because when I'm with people, a lot of people, more than one, and I'm trying to talk with people, and I ask a question, they'll look at everyone except me. And that's the thing that really hurts me." Joanne's poem "Being Heard" eloquently portrays her pain at being excluded and her longing for acceptance. She speaks of the damage to her soul and the other person's loss at not listening. She goes even further, announcing that in her face one might even see a reflection of the love of Christ. She ends with the following stanza:

> Yes, I am disabled but,
> I am important
> I am human
> I am God's servant
> I am worthy of being heard.[39]

She affirms her value in the very place where others question it. She claims the value of her speech when others ignore it. This is a very bold move. Joanne proclaims a counter-cultural message which challenges society's view that women with dis/abilities have less value than other people.

James Nelson states that theology—body theology—begins with "concrete, particular, existing individuals" and involves "critical reflection on our bodily experience as a fundamental realm of the experience of God."[40] Joanne's reflection on her experience as a woman with a dis/ability causes her to claim her whole-person, embodied experience as a worthy and important human being who serves God and has a dis/ability. Dis/ability, full humanity, relatedness to God, and value all go together in the same person. Joanne is worthy of engaging the world in conversation and being heard—she, in

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[39] "My Father's Vessel," photocopied collection of poetry and prose written mainly by Joanne.
[40] James B. Nelson, *Body Theology* (Louisville: Westminster John Knox Press, 1992), 41, 43.

her bodily self which includes femaleness and dis/abilities, has value. Pailin argues that it is the love of God (and others) for a person that gives that person intrinsic value.[41] Furthermore, the Holy One "gives to each person the ultimate dignity of being recognized" as the person each one is in any given moment.[42] Therefore, we can say with Joanne that she, and every other human being, should be accorded the dignity that the Sacred One has already bestowed.

Theologians and psychologists alike are intrigued with the inherent move toward life and the resistance of that which threatens it. Pastoral theologian Kathleen Greider has explored aggression in human beings and society. She argues persuasively for us to consider the complexities of human aggression that include constructive as well as destructive forms. Drawing on depth psychology, she alerts us to a form of aggression that is generally neglected in the common parlance and understanding of the word "aggression"—vitality. Vitality is "the nearly indestructible psychobiological will to survive and thrive"[43] and an "essential aliveness and life-affirmation."[44] In addition, it propels one into action. Vitality "animates us and causes us to act in defense of life—our own and others'."[45] Vitality is essential in the drive to resist annihilation.

Theologian Elisabeth Moltmann-Wendel, in her work on a theology of embodiment, refers to the human body as a "field of energy," using the term in connection with Jesus' healing energies when he recognized that a "power had gone forth from him" as the woman who had been bleeding for twelve years was immediately

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[41] David A. Pailin, *A Gentle Touch* (London: SPCK, 1992), 95.
[42] Pailin, 185.
[43] Kathleen J. Greider, *Reckoning with Aggression* (Louisville: Westminster John Knox Press, 1997), 21.
[44] Greider, 9.
[45] Greider, 21.

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healed of the hemorrhage.[46] "[T]he [human] body—like nature and the earth—has a dynamic of its own."[47] This bodily force has something to do with the immanent Divine, for "God is there in bodies and their energies, alive and active."[48] The healing narratives in scripture have been a source of pain for persons with dis/abilities, so let me hasten to add that, though Moltmann-Wendel points out this energy in connection with a healing event, we should not make the false assumption that the energy in bodies and communicated through bodies is in any way dependent upon a body's cure from impairments.

The stories of Jesus interacting with women with dis/abilities have traditionally been interpreted to connect faith, cure, and well-being. And, indeed, those elements are present in the episodes. Also present within these episodes is a man who restores relationships, especially relationships between an estranged individual and her community. Gospel writers depict Jesus as one who reached across and broke barriers separating people of social and religious esteem from those with little social or religious value. He ascribed value to those he touched, both literally and figuratively. In so doing, he challenged the status quo of religiously sanctioned prejudice against women, people with dis/abilities, and people with both characteristics.

Moltmann-Wendel argues that the healings Jesus performs for women are of a different character and not the "classic illnesses" of which men are cured. "[T]he healings have much more far-reaching consequences than simply the regeneration of an organ. . . . In any healing of a woman a greater social relationship is restored, one which

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[46] Elisabeth Moltmann-Wendel, *I Am My Body* (New York: Continuum, 1995), viii, in connection with Mark 5.24-34.
[47] Moltmann-Wendel, 3.
[48] Moltmann-Wendel, x.

was lost or perhaps was never there."[49] It is not the absence of dis/ability that enables

well-being. Rather, the reestablishment of the value of a devalued person and the reunion

of a disconnected person with her community are symbols of healing.

Liberation comes when barriers are broken down and all people are welcomed

and belong. Homiletician Kathy Black links the liberating intentions of the healing

events with reconnection to one's community.

> The biblical healing texts were intended to be liberating events for those whom
> Jesus healed. Though they had been excluded from the worshiping community
> and from society at large because of their disability, Jesus' acts allowed them to
> be full participants in their religious, secular, and domestic spheres. The healing
> was liberating because it meant incorporation back into these communities.[50]

The cures are the method of, but not essential to, the desired outcome—restoration of

relationships.

Religious leaders are called to challenge forms of annihilation by revisiting and

revisioning theology and by joining women with dis/abilities in resisting death-dealing

circumstances for all. Annihilation of humans due to variations in ability is not of God.

The promotion of death—whether psychological, spiritual, or physical—for certain

persons because they are less valued by society is wrong. Such annihilation opposes the

life-giving activity of God inherent in both biblical testaments. The extent to which the

life-giving theme is not fully developed, or the extent to which the original biblical

writers, bound by their circumstances, make less use of it than might be possible or

conceivable in our day, does not mitigate the opportunity of contemporary Christians to

develop those themes more fully and integrate them in our circumstances in new ways.

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[49] Moltmann-Wendel, 58.

[50] Kathy Black, *A Healing Homeltic* (Nashville: Abingdon Press, 1996), 12.

Nancy Eiesland responds to the need for transformation of the Christian church's theology, symbols, and practices in ways that speak to the situation of people with dis/abilities by resymbolizing the Risen Christ as the Impaired One. "In the resurrected Jesus Christ, [the disciples] saw not the suffering servant for whom the last and most important word was tragedy and sin, but the disabled God who embodied both impaired hands and feet and pierced side and the imago Dei."[51] With this new symbolism, Eiesland is able to assert that "full personhood is fully compatible with the experience of disability."[52]

In spiritual reflection, one sign that an experience is of God is that it is "life-giving" rather than "death-dealing." The life-giving spirit of God is identified with what promotes well-being and not what is demeaning to or degrading of life and lives. This conviction guides the work of pastoral theologians and ministries of care—to call forth, in theory and practice, that which cultivates the well-being of all persons and uproot that which devalues the lives of persons or communities.

Annihilation: Not Even a Woman

Women with dis/abilities face the threat of annihilation as women. Dis/ability functions as a "master category," that is, a category which overshadows, or even erases, the multitude of other particularities a woman possesses. Women with dis/abilities report not being viewed as belonging to the subset of people called women. As noted in chapter 4, the stare as oppressive gaze limits what the eye of culture can see. When a society sees only dis/ability, this functions to erase from society's vision, expectations, and comprehension the "womanliness" or "femininity" of women with dis/abilities. The

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[51] Nancy L. Eiesland, *The Disabled God* (Nashville: Abingdon Press, 1994), 99.
[52] Eiesland, 100.

characteristics comprising "womanliness" or "femininity" are highly contested. One of the controversies between nondisabled feminists and women with dis/abilities, including some who consider themselves feminist, concerns feminist critique of stereotypical representations of women as sexual objects and as wives and mothers. Many women with dis/abilities do not have the roles of wife or partner and mother open to them. Some would not mind being viewed as sexual beings. Though June Cleaver and other 1950's female icons did not work outside the home, today it is common for women to be employed. Many women with dis/abilities would like the option of employment available to them. Many women with dis/abilities are tired of being seen primarily as other, not recognized as women with whatever characteristics that may include, even the most stereotypical ones—sexually attractive, nurturing, and employable.

Women with visible dis/abilities are frequently considered unattractive and asexual, because they transgress cultural standards of attractiveness. A survey by John William Hanna and Betsy Rogovsky "found that the concept 'woman' is often linked with associations of beauty, whereas 'disabled woman' evokes such associations as 'ugly' and 'unpleasant.'"[53] As an adolescent, Deborah Kent thought that finding a mate and, therefore, fulfillment as a woman would be impossible for her because she had a dis/ability.

> By the dawn of adolescence I had absorbed enough innuendoes to suspect that, no matter what social graces I managed to cultivate, no matter how I dressed or wore my hair, I would never be the kind of girl boys wanted to flirt with or to ask on dates. My reading heightened my apprehensions about the future. In books, it seemed, the only way a woman could be fulfilled was through the love of a man; and the only women worthy of that love were lithe and lovely, unblemished, physically perfect. The smallest flaw—an uneven gait, a malformed hand, a squint—was enough to disqualify a woman from romance, from all hope for

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[53] John William Hanna and Betsy Rogovsky, "Women with Disabilities," *Disability, Handicap and Society* 6, no. 1 (1991): 57.

happiness. If even a trifling imperfection could loom as such an insurmountable obstacle to fulfillment, what chance was there for a girl who was totally blind, as I was?[54]

Nancy Mairs, who writes about her experiences as a woman with multiple sclerosis, speaks of a time when she needed to know that men still found her attractive despite the noticeable symptoms of MS. This was at least one of the factors that led her into a series of casual affairs.[55]

Sexual attention toward women with dis/abilities is presumed to be neither warranted, desired, nor appropriate. Eli Clare records the story a friend told her.

> *When I was in high school, I'd go cruising with my girl friends. The boys would hoot and holler at us, Hey baby, you're hot, or just wolf whistle. But later if they saw my leg braces and crutches, they come over to me, quietly apologize, tell me they didn't mean it.*[56]

Clearly, the boys had learned that a girl with a dis/ability is not one at whom to hoot, holler, and whistle. Furthermore, the boys assumed she was offended or hurt by the attention. The dis/ability cancels out her attractiveness and desirability and also the possibility that she might like another to notice her as a sexual being. Edie recalled a painful episode in her life. A young man who attended college with her, upon hearing about her accident, responded, "I was going to ask her out." Edie explains how she understands that comment: "So, in other words, 'Now I'm not going to—there's something wrong.'" Dis/ability eliminated her as a person he would want to date.

Sexuality is, of course, more than sexual activity or desire. It is also about being and feeling like a woman, about being noticed and affirmed as a woman. Rebecca

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[54] Deborah Kent, "In Search of a Heroine," in *Women with Disabilities*, ed. Michelle Fine and Adrienne Asch (Philadelphia: Temple University Press, 1988), 90. Used by permission.

[55] Nancy Mairs, *Waist-High in the World* (Boston: Beacon Press, 1996), 52.

[56] Clare, 111 [italics in original].

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reported that she occasionally enjoyed going to a local bar to listen to the bands. Before she had a dis/ability, she would regularly be disturbed by men's gestures of, and bids for, attention. She resented this because she had come for the music. Later, after she became disabled, she observed that she was not noticed at all. It was as if she were invisible. She was then in a position to reevaluate the effects of this undesired attention. It had actually been a source of maintaining her self-esteem and her concept of herself as an attractive woman and a sexual being. Edie also remembers a time when she could walk into a bar and receive a great deal of attention. She enjoyed the attention and says that it is important for her to have had that confirmation of her appeal as a woman. Now, she notes, men have to get to know her before they ask her out. She reported that she has more female friends since her accident, which she attributes to women no longer considering her a "threat" to their relationships with their boyfriends.

Asch and Fine suggest that the male gaze, though controversial, confers sexuality and femininity on women.[57] Rebecca's and Edie's experiences seem to confirm this. Some women with dis/abilities express regret at the absence of the appreciative male gaze.[58] Though they may be saved from putting up with unwelcome remarks, the lack of confirmation of womanliness is missed.

Because it was presumed that they were not going to marry or "find" a partner, much less be chosen, some women whose dis/ability occurred early in life report being encouraged to follow a path leading to employment. Work was associated with independence, stereotypically male goals. One woman told researchers Adrienne Asch

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[57] Asch and Fine, 30.
[58] Asch and Fine, 30.

and Michelle Fine: "I was raised to be a non-disabled son."[59] Eli Clare reports that her

father used to take her to work alongside him in building projects, and she could do some

things as well as most men in the area. Clare also writes that, "[E]arly on my father

started raping me, physically abusing me in ways that can only be described as torture,

and sharing my body with other people, mostly men, who did the same."[60] Being

considered asexual does not protect women with dis/abilities against sexual abuse.

Nurturing others is a task that has traditionally been assigned to women. "Women

mother," is Nancy Chodorow's succinct way of putting it.[61] They care for the sick. They

are responsible for the well-being of their husbands (and, until recently, every woman

was advised to have one so, oddly enough, she wouldn't have to take care of herself).

Women are the ones most often called on to care for elderly parents and to lend a helping

hand to neighbors or others in their community. Relationality is generally ascribed to

women. In other words, women are seen as responsible for mothering and for "othering,"

that is, responsible for the well-being of others in general.

In contrast, as mentioned in Chapter 4, a woman marked by the term dis/ability is

assumed to be childlike and needy. In the United States, self-sufficiency is valued.

Anyone who appears to be helpless or have needs is devalued, labeled dependent, and

presumed to be unable to care for others. She is perceived to be unable to give to society

and may be seen as a drain on society. Persons enculturated in societies valuing self-

sufficiency have a very difficult time imagining that it is possible to both need and

appreciate care and to be able to give care.

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[59] Asch and Fine, 24.
[60] Clare, 9.
[61] Nancy Chodorow, *The Reproduction of Mothering* (Berkeley: University of California Press, 1978), 3.

Heterosexual women with dis/abilities are more likely to be never married, divorced, separated, or married living apart, and less likely to have children or intimate relations than either nondisabled women or men with dis/abilities.[62] Likewise, lesbians with dis/abilities also report that they are less sought after as partners, "being dismissed, shunned, or relegated to the status of friend and confidante rather than lover."[63]

In addition to being attractive and nurturing, images of women today often include employment . However, because of the lack of ability associated with the word "dis/ability," potential employers may have trouble viewing women with dis/abilities as competent employees. This is true for men with dis/abilities, but not to the same extent. Women with dis/abilities are less likely to be employed than nondisabled women or men with dis/abilities, and this occurs "[a]t every level of education, including the highest."[64]

The nondisabled public's impression that persons with dis/abilities are unemployable is not new. The play "P.H.*reaks" points out that under Franklin Roosevelt's new deal program, which put unemployed people to work, persons with dis/abilities had PH stamped on their paperwork. PH stood for "physically handicapped" and designated a person as unable to meet the standards of the program, that is, PH meant one was labeled unemployable.[65] Dis/ability has signified unemployability since industrialization and the Elizabethan Poor Laws. People with dis/abilities were legally defined as able to receive poor relief because they were assumed to be unable to work.[66]

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[62] Hanna and Rogovsky, 52.

[63] Asch and Fine, 19.

[64] Hanna and Rogovsky, 53.

[65] Doris Baizley and Victoria Ann-Lewis, adaptors, "Selected Scenes from 'P.H.*reaks,'" in *Staring Back*, ed. Kenny Fries (New York: Plume, 1997), 320.

[66] Debra Connors, "Disability, Sexism and the Social Order," in *With the Power of each Breath*, ed. Susan E. Browne, Debra Connors, and Nanci Stern (Pittsburgh: Cleis Press, 1985), 93-95.

Unfortunately, this association has stuck, even though many people with dis/abilities are capable and eager workers.

Resistance: "I Know I Look Fine"

As recorded above, Audre Lorde proclaims, "I knew I looked fine" as she finishes her preparations to go out for the first time following her mastectomy. Many women with dis/abilities have that same kind of confidence in themselves as they go about being the persons they are.

Cultural representations of women's appearance and sexuality do play a part in how women with (and without) dis/abilities are seen. However, that is not the whole story. Many women with disabilities know others, men and women, who do indeed find them attractive, confirm their womanliness, and with whom they engage in mutual and loving (rather than oppressive) gazing. Not the dominant responses to them, but these experiences are important because they offer a source of alternative knowledge and narratives.

Of the five women I interviewed, one was currently living with a partner. Three women indicated that they had been in relationships (including one woman who had been married) that had ended. One woman stated that she was not at all interested in a sexually intimate relationship. Another woman said that, had the dis/ability not occurred, she probably would be married with children. She believed that dis/ability had an affect on personal relationships, but she was not disappointed in the way her life turned out.

Some women with dis/abilities consider themselves attractive, whether or not others do. Diane DeVries, a woman born with partial limbs, is one of those women. Her biographer, Geyla Frank, notes that DeVries'

self-image was really very positive. But it was only through a leap of communication, a metaphor [Venus de Milo], that I was able to grasp an essential feature of her self-concept—the fact that she conceived of her body as lovely. . . . Her body need not be seen from the point of view of its deficits but, rather, as integrated and complete. This is, I believe, the dominant mode in which Diane experiences her embodiment.[67]

Frank acknowledges surprise at DeVries' positive view of her body. Frank attributes her surprise to her own "preconceptions about disability."[68] DeVries' narrative of her own body challenges cultural messages of disabled bodies as asexual and ugly.

Cultural messages about women with dis/abilities not being capable mothers has not deterred them from being capable mothers. Sylvia Dick Gomez is a woman with multiple sclerosis who writes an alternative narrative through her poetry. In one poem, "Reflections of a Mama Bear," she tells a story of dis/ability and value as she subtly contrasts the value society assigns her and the value her young daughter sees in her.[69] The poem depicts her daughter at play in several scenes revolving around the scooter or wheelchair Gomez uses for mobility. In one scene, her daughter lines up her young friends to take turns riding with Gomez on the scooter. In other scenes, the chair becomes a rock for mermaids or a "Wise Women's Lodge." At yet another point in the poem, daughter joins mother on the scooter as they make their way down the street seeing themselves as eagles, astronauts, and bears with the store windows mirroring their travels. In the midst of these wonderful adventures, Gomez reports an onlooker's comment, "'It must be hard for her to see you like this.'" At first, that line seems disconnected from the rest of the poem—until the very end when Gomez give thanks for

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[67] Frank, "On Embodiment," 65.
[68] Frank, "On Embodiment," 65.
[69] Sylvia Dick Gomez, "Reflections of a Mama Bear," *Bigger than the Sky*, ed. Michele Wates and Rowen Jade (London: Women's Press, 1999), 138-39.

a child who "sees me as I am." The onlooker assumes the daughter is distressed by her mother's dis/ability. But, no, the poem conveys a child who sees her mother as a capable, imaginative, and adventuresome person—the woman her mother is.

None of the women I interviewed were mothers, but several took an interest in children. Joanne hurdled a number of obstacles to get a degree in early childhood education. Liz has taken a child with a dis/ability and his mother under her wings, offering the child encouragement and the wisdom of experience to pursue some of his interests and giving his mother advice on ways to advocate for and be supportive of him. Rebecca takes particular care in being responsive to children who notice or ask questions about her dis/ability. All had relationships in their lives which were important to them—friends, family, colleagues—in which the "othering" was mutual.

Dis/ability and work are not mutually exclusive in the lives of women with dis/abilities. Of the women I interviewed, both Camille, the artist, and Liz, an executive, worked full time at jobs they loved. Edie was looking for a job and expected to find a suitable one. Rebecca was a full time graduate student. Joanne was unemployed, yet wrote poetry and was active in her community of faith and her denomination. Some of the resources I use throughout this work are by women with dis/abilities who are prominent in their respective fields, e.g., writers Nancy Mairs and Eli Clare, university professors Susan Wendell and Rosemarie Garland Thomson, seminary professors Kathy Black and Nancy Eiesland, and therapist Harilyn Russo.

In the following chapter, our perspective changes from the exclusive negative phenomenon of annihilation to the potentially constructive phenomenon of mirroring. I

examine the stare as a mirror in which women with dis/abilities see negative cultural representations of dis/ability reflected in the eyes and faces of some persons, usually strangers. Fortunately, affirming personal relationships with friends, family, communities of faith, and God "mirror" the full personhood a woman with a dis/abilty knows herself to have and, thus, aid both in recovering from harmful interactions and in resisting the devaluation, when possible.

CHAPTER 6

THE FACE AS MIRROR: A CULTURAL PHENOMENON

The previous two chapters explored contours of cultural attitudes toward, representations of, and actions against women with visible physical dis/abilities, as well as the alternative narratives their lives construct. In this chapter, I examine interpersonal interactions as a means of communicating to women with visible dis/abilities how society in general sees them. In the first section, "The Psychoanalytic Concept of Mirroring," I offer a brief account of the psychoanalytic concept of mirroring and the implications it has for personality development when mirroring is adequate and when it fails. The stare is an example of failed mirroring. While exploring extensively the experiences of children with dis/abilities is beyond the scope of this work, I note the importance of adequate mirroring for them in light of the challenges they face in the wider culture. In the second section, "The Distorted Image," I introduce theories about individual and cultural factors that influence the images projected on women with dis/abilities. The third section, "The Stare as Failed Mirroring," presents a story of the stare told by Rebecca and analyzes it as a mirroring experience that reflects a distorted image. Failed mirroring is harmful to a person, but with "Restorative Relationships," the topic of the fourth section, some of the damage can be prevented or healed. "The Mirroring Face of the Holy" is the fifth section. Though some people understand religious traditions and practice to suggest that God views people with dis/abilities as monstrous and sinful, other persons see in the face of the Divine a loving, caring, welcoming, and accepting presence.

The Psychoanalytic Concept of Mirroring

Mirroring is a process by which one sees oneself in the face of another, a process of being shown and knowing oneself through interactions with another.[1] Though the concept of mirroring stresses the visual components in the process, the other senses also play a role in mirroring.[2] Mirroring begins in the relationship between infants and their parents, or other early childcare providers. However, this concept has implications for all relationships. When mirroring goes well, a person is left with an accurate and positive representation of herself and reasonably healthy self-esteem; mirroring fails when the individual is confronted with a distortion of herself, and her sense of self-worth is damaged. Encounters with the stare are experiences of failed mirroring.

British pediatrician and psychoanalyst D.W. Winnicott proposed that in the course of a child's personality development, parents and other primary childcare providers serve a mirroring role. That is, parents, and especially their faces, function as a mirror to the infant. "What does the baby see when he or she looks at the mother's face? I am suggesting that, ordinarily, what the baby sees is himself or herself. In other words the mother is looking at the baby and *what she looks like is related to what she sees there.*"[3] In "good enough" parenting the mother's or father's reflection of the child is close

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[1] Mirroring is a concept that is used in the field of psychology with diverse meanings. For example, Rhoda Olkin, *What Psychotherapists Should Know about Disability* (New York: Guilford Press, 1999), 12, uses the word "mirror" to refer to the phenomenon of imagining that the bodies of persons with whom one regularly interacts reflect oneself. She writes, "[m]ost people with disabilities are surrounded by people without disabilities, and thus see mirrored back to them nondisabled bodies and movements." She goes on to make the point that these people, especially if their disability is relatively mild or moderate, are more likely to identify with nondisabled people. I am using the term "mirroring" as it is used in object relations theory, to discuss relationships that communicate something about the woman in particular, including but not limited to her body.

[2] This is an important awareness when considering the implications of mirroring in the lives of infants and/or parents who are blind. "[B]lind infants need to get themselves reflected through other senses than that of sight. Indeed, a mother whose face is fixed may be able to respond in some other way." D.W. Winnicott, *Playing and Reality* (New York: Routledge, 1989), 112.

[3] Winnicott, 112.

enough so that the child experiences that, "[w]hen I look I am seen, so I exist."[4] The

infant's presence is acknowledged and her personhood is recognized. Something about

the real child is seen and reflected back to the baby, and therefore communicates to the

baby her actual existence. According to psychiatrist and psychoanalyst Ana-Maria

Rizzuto, the very earliest experiences between parents and child are crucial to forming

the child's representation of herself. "The mother is there to give the child a

representation of himself, to tell him what he looks like, call him by name, and tell him

the names of the parts of his face and then of his body."[5] A young child learns about

herself through the mirroring process.

Whereas Winnicott emphasizes the parental face as mirror, Rizzuto also sees

mirroring at work in other aspects of care within the context of the extended family and

the various associations the family develops within the community and world.[6]

> [T]he mirroring importance of the maternal face, which begins with eye contact,
> expands during the first month of life to encompass sequentially the mother's
> face, the total handling of the child, the mother's fantasies and wishes, her
> mythological elaboration of the child's identity, her overt or covert wishes, and
> her demands that the child in turn mirror her wishes. All this happens in the
> wider context of family romances and myths between parents, grandparents, other
> children, the religious and political background of the family—in a word, within
> the entire familial mythologization of everyday life.[7]

Society is among contextual influences that activate a family's or community's

imagination about each child. Social, religious, and political values impinge on the

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[4] Winnicott, 114. "Good enough" parenting is Winnicott's term to express his theory that parents
need not be perfect, and that perfection in the parents is not even desirable. No parent is perfect, of course,
though those who try to meet all the needs or demands of a child do a disservice to the child in the long run.
Perfection in a parent would interfere in some tasks the child needs to do herself.

[5] Ana-Maria Rizzuto, *The Birth of the Living God: A Psychoanalytic Study* (Chicago: University
of Chicago Press, 1979), 185-86.

[6] Winnicott acknowledges that other relational interactions may serve a similar function as looking
into a parent's face, but he sees them as compensatory, 112.

[7] Rizzuto, 186.

family and the family's understanding of the child, whether the child is a girl or a boy, light skinned or dark skinned, lives in poverty or wealth, is nondisabled or has a dis/ability, speaks the dominant language or another one.

Through mirroring interactions with her parents and community, the young child learns that she exists, what she looks like, how she is imaged, what her body is like, where she fits in the family story, and whether and how she is valued. Psychoanalyst Heinz Kohut theorized that two types of parent-child relationships are essential for the formation of healthy psychological functioning—a mirroring relationship and an idealizing relationship.[8] In an adequate mirroring relationship, the parent focuses on the child's healthy "grandiosity" and "exhibitionistic" tendencies. The child gladly demonstrates her growing capabilities to her parent who proudly relishes and applauds them. Thus, the parent confirms the infant's "primary narcissism," that is, the young child's natural sense of perfection and omnipotence. When adequate mirroring occurs, the child knows herself to be a wonderful creature. "I am perfect and you admire me."[9] "Good enough" mirroring happens when persons interact with a child in such a way as to "respond to and confirm the child's innate sense of vigour, greatness and perfection."[10]

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[8] Jay R. Greenberg and Stephen A. Mitchell, *Object Relations in Psychoanalytic Theory* (Cambridge: Harvard University Press, 1983), 354. I draw on a number of other works in the following synthesis of Kohut's basic theory. Heinz Kohut and Ernest S. Wolf, "The Disorders of the Self and Their Treatment: An Outline," *International Journal of Psycho-Analysis* 59 (1978): 413-25; Heinz Kohut, *The Analysis of the Self* (New York: International Universities Press, 1971), 105-32; Heinz Kohut, "Forms and Transformations of Narcissism," in *The Search for the Self*, vol. 1, ed. Paul H. Ornstein (New York: International Universities Press, 1978), 427-60; Heinz Kohut, "The Psychoanalytic Treatment of Narcissistic Personality Disorders: Outline of a Systematic Approach," in *Search*, vol. 1, 477-509; and Heinz Kohut, "Thoughts on Narcissism and Narcissistic Rage," in *The Search for the Self*, vol. 2, ed. Paul H. Ornstein (New York: International Universities Press, 1978), 615-58.

[9] Greenberg and Mitchell, 354.

[10] Kohut and Wolf, 414.

The infant's original narcissistic confidence in her perfection and omnipotence, Kohut contends, are the basis for healthy self-esteem and ambition. In the idealizing relationship, the parent allows the child to glory in the parent's perceived perfection and to feel a part of it. This relationship sets the stage for the child's development of ideals and values. Some failures in the mirroring and idealizing relationships are inevitable and necessary. In optimal development, minor and gradual parental failings result in two positive outcomes—the child's perception of self and other becomes more realistic, and the child's psychic structures begin to internalize the healthy aspects of the mirroring and idealizing relationships. This lays the foundation for a realistic confidence in oneself and one's capacities and for the ability to pursue one's ideals and values.

In an adequate mirroring relationship, parental response and confirmation involve a recognition of characteristics the child possesses or believes she possesses. The adult who functions as the mirror is revealing something that is already sensed by the child. Thus, the term "mirror" assumes a largely accurate recognition and reflection of what is present. For a child or an adult to believe she possesses particular abilities in which others delight can be interpreted as a sign of her confidence in herself and her abilities, and therefore, an indication of healthy self-esteem and ambition. The expression of true confidence and joy in oneself and one's abilities are outcomes of reasonably accurate mirroring and are essential traits to be admired and encouraged.

Because cultural representations of the disabled body portray abnormality and a life not worth living, parents, clergy, and society at large may have a difficult time responding to the child or adult with a dis/ability with genuine admiration and joy at the

person's demonstration of capabilities and self-confidence.[11] Yet, an affirming mirroring

relationship is crucial to the well-being of all persons. Like their nondisabled peers,

children with dis/abilities need adequate and accurate mirroring to grow into adults who

are confident in their abilities and knowledgeable about their limits, especially since

modern culture tends to exaggerate the limitations and minimize the abilities of persons

with dis/abilities.

Some parents and primary caregivers are unable to provide their children with the

necessary mirroring. What happens when mirroring fails? The problem comes not with

occasional failures of "good enough" parenting. Rather, a failure in mirroring occurs

when mirroring is habitually inadequate or inaccurate. Instances in which mirroring fails

involve parents whose depressive state preoccupies them, whose defenses make them

incapable of mirroring, or who seem to be talking to someone else and not the infant

herself. Though the infant repeatedly looks into such faces for a view of herself, she

never or rarely sees it. Instead, she sees a fixed, unresponsive expression or a face

responding to something else entirely.[12] This is a one-sided relationship. The infant

seeks to engage the parent, but the parent is unable to respond. Such babies "have a long

experience of not getting back what they are giving."[13] Failed mirroring lacks the natural

reciprocity of a more healthy parent-child relationship. The baby gives more of herself to

the relationship than does the adult; the baby sees, but is not seen. When that happens,

the infants "look and they do not see themselves."[14]

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[11] See Chapter 4 for a discussion on cultural representations and portrayals of abnormality and Chapter 5 on the worthwhile nature of a life with a dis/ability.

[12] Winnicott, 112, 113, 116-17.

[13] Winnicott, 122.

[14] Winnicott, 122.

Rizzuto identifies an additional failure of mirroring: a parent reflecting the parent's fantasies for the child but not the real child. The representation the child sees is an exalted child, as opposed to a normally wonderful child, so the child fails to get a true picture of herself.[15] She is not seen as she is but as the parent hopes her to be.

Philosopher David Michael Levin argues that modern empirical society is marked by restricted vision and needs to be open to a vision that includes more than merely what can be observed through sight. Levin discusses the difference between an "assertoric" gaze and an "aletheic" gaze. The assertoric gaze corresponds to what I call the stare. It sees from "only one perspective, one standpoint, one and only one *position*. . . . [and] therefore tend[s] to be narrow, dogmatic, intolerant, rigid, fixed, inflexible, and unmoved: in sum, not very caring."[16] Some aspects of failed mirroring involve the restricted vision of the assertoric gaze. In contrast, the aletheic gaze is inclusive, caring, interdependent, and reciprocal.[17] It "is a gaze that can encourage others to be true to themselves, so that they may develop their ownmost potentialities."[18] Such are characteristics of mostly accurate mirroring and affirming relationships.

Mirroring and failed mirroring take place throughout life. If a solid sense of self has been built up in one's infancy and early childhood, the effects of failed mirroring are not as traumatic as if the sense of self were distorted from the beginning. However, continued inaccurate mirroring, even with the formation of a solid self, is not without

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[15] Rizzuto, 187.
[16] David Michael Levin, *The Opening of Vision* (New York: Routledge, 1988), 440. Bill Hughes, in "The Constitution of Impairment," *Disability and Society* 14, no. 2 (1999), makes reference on p. 166 and 168 to the assertoric gaze in Levin's work and identifies the difference between assertoric and alethetic gazes in a footnote, 170, n. 5.
[17] Levin, 439.
[18] Levin, 439.

effect. Parents can lay a good foundation that failed mirroring in public life undermines. Society to a large extent mirrors inadequately. In the stare, women with visible dis/abilities often find themselves seen as one is not, rather than as one is. That is, they too often see themselves mirrored as grown-up poster children or pitiful creatures in need of help rather than as women with abilities and adventuresome spirits toward life. The mirror is distorted—like "funhouse" mirrors, in which one sees an exaggerated version of oneself with an unrecognizable shape.

An infant experiencing inadequate mirroring may find other ways to get what she needs from the environment. For example, a parent may be able to respond in ways other than facial expressions or may respond at especially crucial times, such as when the child is in distress.[19] Sometimes, the infant gives up expecting the parent's face to function as a mirror and learns to read the face as a barometer that predicts the relative safety of being herself and letting her spontaneous self "come out and play." As a last resort, the infant may simply withdraw, having learned not to expect any meaningful exchange.[20] Of course, each response indicates a great loss—the absence of a mutual interaction in which a parent can delight in the child, the child can experience herself being seen and enjoyed, and vice versa.

Experiencing chronically or traumatically inadequate mirroring, whether as an infant, child, or adult, causes harm in at least three ways. One effect of failed mirroring is the failure to recognize the person who exists in one's own self, with abilities and limitations. If the familial or cultural mirror reflecting a woman with a dis/ability is

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[19] An ability to respond through means other than facial expressions is also an important dimension of the mirroring relationship for parents or infants who are blind. Winnicott, 112.

[20] Winnicott, 112-13.

cracked or distorted, then a piece of information important for self-recognition is missing. When a woman sees primarily her limitations mirrored by society, her abilities remain unconfirmed. When the mirrored limitations are exaggerated, it is difficult realistically to assess and know the boundaries of one's limits, suggesting that one's limits are all-encompassing. In these ways, failure of relationships to confirm realistic limitations and abilities damages a person's well-being.

The second effect of distorted mirroring is lack of recognition of one's value, one's acceptability as one is. Each person needs to know from others that she is acceptable by the important people in her life. Rizzuto speaks of this in terms of the child being small and needing big and powerful adults, and God, to survive. She needs someone who really knows her and recognizes her as an acceptable child.

> All the child can do is hope to be found acceptable. If he is, he can relax. But if, at this stage of more mature mirroring, confirmed now by the child's first observations of his own behavior, the image formed and reflected is that of a bad child who has not fulfilled the mythological mission assigned by the parents, there is a conflict of *being*. The child senses that what is wrong is not what the child does but what he is.[21]

Rizzuto writes about parents or God as the big and powerful person who finds—or does not find—the child acceptable. Also, society is an influential force in the life of individuals and plays a major role in assigning expectations of personhood, making decisions about whether and to what extent one lives up to those expectations, and making pronouncements about whether a person is worthy of life. When people with dis/abilities are viewed as failing to fulfill society's expectations of what a body should

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[21] Rizzuto, 188 [emphasis original].

be or do, the story told by failed mirroring through the stare is that the being of the person is what is wrong.

Third, failed mirroring damages current and potential relationships. It fails to equip the individual for the natural give-and-take, the easy reciprocity, inherent in mutual relationships. When the failed mirroring relationship takes place early in life, parent and child do not get to know each other as they are individually nor as they could be in relationship. The same can be said for society and women with dis/abilities or any disenfranchised group. The person who stares, believing dominant cultural views, does not get to see a person with a dis/ability as she is. Therefore, the possibility for a mutual, interdependent relationship is lessened or nonexistent. To live without mutual, interdependent relationships in one's life is a loss to nondisabled persons as well as to persons with dis/abilities.

According to Kohut, mirroring in the parent-child relationship fails because of pathology in the parents.[22] For the parent-child relationship, parents' capacity to maintain confidence both in the child when the child is exposed to her own limitations and in themselves when the child becomes aware of the parent's weaknesses are crucial milestones.[23] Parents happily mirroring the child's grandiosity one moment, and realistically and non-anxiously facing the child's limitations in the next moment, facilitate an adequate development of the self. However, if the parent or primary caregiver consistently ignores the child's needs in favor of meeting her or his own needs, the child is likely to have great difficulty developing a secure self.[24]

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[22] Greenberg and Mitchell, 355.
[23] Kohut and Wolf, 417.
[24] Kohut and Wolf, 417.

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If failure to mirror adequately over time has something to do with a disturbance in the party that cannot give back what is given, nor recognize and acknowledge what is present, then society's inability to mirror accurately reflects damage within society itself. Anthropologist Robert Murphy claims that "the avoidances and even outright hostility so often manifested toward them [the disabled] by the non-disabled are not the natural products of their own physical deficits but, rather, expressions of deficiencies of perspective and character of those who so behave. . . ."[25] This is, as noted in chapter 2, the claim that the social-political model of dis/ability makes. Society, through the ways it constructs the disabled body, the choices it makes about architecture and attitudes, and the way it mirrors, is a major source of disablement of persons with dis/abilities, much more than a functional limitation itself.

The Distorted Image

Some dis/ability scholars propose that nondisabled use people with dis/abilities psychologically as receptacles for nondisabled persons' unwanted and projected parts. Deborah Marks utilizes psychoanalytic concepts of splitting and projection to explain this phenomenon in the psyche of nondisabled people as it relates to a "narcissistic culture in which people strive for 'perfection' and 'independence.'"[26] No one lives up to cultural expectations. We all have some "bodily imperfections and dependency."[27] Psychoanalytic theory posits that we project onto others those aspects of ourselves that we do not want to acknowledge. Typically, this psychological process is unconscious.

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[25] Robert F. Murphy, *The Body Silent* (New York: W.W. Norton, 1990), vi.
[26] Deborah Marks, *Disability: Controversial Debates and Psychosocial Perspectives* (London: Routledge, 1999), 21.
[27] Marks, 21.

Persons with dis/abilities, "hav[ing] been socially constituted as damaged," thus are treated as the wastebaskets for the split off and projected parts of nondisabled people.[28] If we imagine a literal reel of film having previously recorded one's imperfections and dependencies now being run through the appropriate psychic equipment and projected onto a screen, we have an idea of the psychoanalytic concepts of the defense mechanisms of splitting and projection. The unacknowledged and disavowed parts of an individual have been put, metaphorically speaking, on a reel of film. Marks theorizes that, when a nondisabled person meets persons with dis/abilities, the first person's unacceptable characteristics unconsciously are seen as parts of the individuals who are already set up to be seen as damaged goods, because the latter possess what society has identified as defects. Because it is a projection, it says little or nothing about the persons with dis/abilities and a great deal about the "film's" contents, that is, the observer's disavowed features. Therefore, what others see in persons with dis/abilities is often not something confirmed by reality. When this happens, whatever is seen is not what is present. What is present conjures up something that is unrelated to women with dis/abilities.

However, the concepts of splitting and projection do not fully explain the cultural dynamics at work in the devaluation of women with dis/abilities. Stanley Kaplan and Roy Whitman[29] contribute to this phenomenon the concept of the negative ego-ideal, which consists of the "internalized negative standards of the parents and culture."[30] It is

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[28] Marks, 20-23, esp. 21.

[29] Kohut refers in a footnote to the work of Kaplan and Whitman on prejudice. See Kohut, *Analysis*, 106, n. 1.

[30] Stanley M. Kaplan and Roy M. Whitman, "The Negative Ego-Ideal," *International Journal of Psycho-Analysis* 46 (1965): 186.

more than simply an individual's lack of perfection and fear of dependency that gets internalized and projected. Culture is a part of the system. Persons within a particular cultural system internalize a message of what is unacceptable behavior in that culture.

When we relate this to issues of dis/ability, it suggests that women with dis/abilities behave in culturally unacceptable ways. Clare notes that bodily associations with gender are set by the typical motions of nondisabled people. "A woman who walks with crutches does not walk like a 'woman.'"[31] The positive ego-ideal is defined as a "hypothetical standard of perfection."[32] Society has its standards of perfection for women. Nancy Mairs, in her popular essay, "On Being a Cripple," describes the ideal woman of our era.

> Today's ideal woman, who lives on the glossy pages of dozens of magazines, seems to be between the ages of eighteen and twenty-five; her hair has body, her teeth flash white, her breath smells minty, her underarms are dry; she has a career but is still a fabulous cook, especially of meals that take less than twenty minutes to prepare; she does not ordinarily appear to have a husband or children; she is trim and deeply tanned; she jogs, swims, plays tennis, rides a bicycle, sails, but does not bowl; she travels widely, even to out-of-the-way places like Finland and Samoa, always in the company of the ideal man, who possesses a nearly identical set of characteristics. There are a few exceptions. Though usually white and often blonde, she may be black, Hispanic, Asian, or Native American, as long as she is unusually sleek. She may be old, provided she is selling a laxative or is Lauren Bacall. If she is selling a detergent, she may be married and have a flock of strikingly messy children. But she is never a cripple.[33]

It is risky to use the word "never." As we saw in Chapter 5, dis/ability functions as a master category and overshadows or erases all other characteristics. However, at least two women with dis/abilities have made it into the "glossy pages." Aimee Mullins,

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[31] Clare, 112.

[32] Roy M. Whitman and Stanley M. Kaplan, "Clinical, Cultural and Literary Elaborations of the Negative Ego-Ideal," *Comprehensive Psychiatry* 9 (July 1968): 358.

[33] Nancy Mairs, "On Being a Cripple," *Plaintext* (Tucson: University of Arizona Press, 1986), 16. Used by permission of the University of Arizona Press.

a model before the accident that resulted in the amputation of both her legs, has

participated in photo shoots wearing several different prostheses, some quite unusual.

Thomson suggests that the photos "mock the fantasy of the perfect body."[34] Ellen Stohl,

a wheelchair user, was a *Playboy* centerfold in 1987, albeit sans wheelchair in the full

page photographs.[35]

Despite at least two exceptions to the "never a cripple" rule, dis/ability seems to

disqualify a woman from fulfilling the positive ego ideal. Culture may allow a rare

woman with a dis/ability into the ranks of those who fill magazine pages or movie

screens, but visible physical dis/ability is not something popular culture holds up for its

citizens to emulate, as one would the positive ego-ideal. Therefore, dis/ability gets

thrown into the pile of other cultural deficits which make up the negative ego-ideal.

Some of the words used to describe both the negative ego-ideal and dis/ability are the

same—inadequate, deficient, defects.[36]

It seems more plausible that what is projected onto women with dis/abilities

includes this cultural component of the negative ego-ideal. Were it personal

"imperfections" and "dependencies" alone, the projections would have more

individualized components rather than the corporate constellation of features attributed to

women with dis/abilities. In the projection process, these images are conjured up by the

nondisabled person and laid on the woman with a dis/ability so that she, as she is,

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[34] Rosemarie Garland Thomson's keynote presentation, "Integrating Disability, Transforming Feminist Theory," including slides, at the Feminism Confronts Disability Conference, February 15, 2002, UCLA Center for the Study of Women, Los Angeles, California.

[35] Clare, 104.

[36] Whitman and Kaplan, 358.

disappears. What she sees in the face of the other person is a mirror of societal

perceptions, not an accurate rendering of herself.

The Stare as Failed Mirroring

Human experience can confirm psychoanalytic theory's relevance to daily life.

This section analyzes a staring encounter experienced by Rebecca and shows how the

concept of mirroring discussed above can illuminate an interpersonal interaction.

Scene 1: "Daily stares"

We enter Rebecca's narrative as she explains the difference between daily stares

and a stare she can't ignore.

> Although they [the daily stares] do build up and bother me over time, one of the
> reasons they don't usually freeze me in my tracks is that whatever is going on is
> unsaid. So I can reinterpret it or I can ignore it in ways that I can't once
> something is actually said. When I think about the instances when I've been
> stared at that have more significantly bothered me, it began as someone staring at
> me, but it led into them saying things to me. So that's all of a sudden a stare that I
> can't ignore, because I know exactly what it means.

Rebecca's overall reaction to stares suggests she had fairly accurate mirroring

experiences in her early years. According to Kohut, inadequate mirroring would result in

a damaged self marked by unstable self-esteem and extreme "sensitiv[ity] to slights,

failures, and disappointments."[37] If this characterized Rebecca, we might expect her to

respond to any glance with a significant drop in self-esteem, perhaps accompanied by

self-chastisement and anger or rage at nearly every person who noticed her.[38]

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[37] Kohut and Wolf, 413.

[38] See Kohut, "Thoughts on Narcissism and Narcissistic Rage," *Search*, vol. 2, 615-58. Though
Kohut's theories of mirroring and failed mirroring are helpful to my analysis of the stare, he himself failed
to appreciate the power of the stare and the damage it can cause. In fact, he suggests that a person with a
"defective body part" is "quasi-delusion[al]" if that person is convinced that others are staring. Kohut does
acknowledge that an individual's "defective organ" may be "scrutinized" by another. He does not state
how "scrutiny" differs from "staring." He seems to dismiss the reality of the stare by associating a patient's
feeling stared at with pathology. In Kohut's view, feeling stared at signals an unsatisfied early childhood
wish to be noticed, which is "projected (with reverse aim)" onto another. See 632, including n. 5. While

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Because, for Rebecca, "good enough" mirroring had already been established,

minor incidents of failed mirroring did not affect her in a largely negative way. Though

her picture of herself has had to undergo changes over the past five or six years, her sense

of herself is rather solid. She can differentiate between stares she can ignore or interpret

in benign ways and stares that contain a negative value judgment. Rebecca has

developed a refined analysis, assessing stares as to their lethality and interpreting them

according to her best interests. The benign stare and the "significant" stare both have

meaning in her system, but she is able to read the more frequent stares in a way that is not

disturbing, at least not in the moment. Because the meaning can be in doubt unless or

until something is said, Rebecca chooses the least offensive interpretation. It allows her

to ignore the many daily stares and get on with life. She performs an act of self-care.

<div style="text-align:center">Scene 2: "A stare that I can't ignore"</div>

Rebecca continues her narrative with an example of a stare that she could not

ignore, that she could not interpret as mere curiosity.

> I was pushing my chair along [a street] right near my apartment, and I think I was
> going to school . . . and this man, he's probably in his late 50's, maybe 40's, he
> was ahead of me as I was pushing towards him and he was staring at me as I was
> coming along the sidewalk. . . . As I was getting closer I could see that he was
> staring at me and I noticed him, but I didn't really think about it because people
> often stare at me. . . . But then as I got closer—usually my experience is people
> will stare at me long enough for me to see them and then they stop, they get
> embarrassed, they look away, and then once they look away they might look
> again. But then it comes into this thing of looking and looking away. But this
> guy . . . never stopped looking at me at all, so that started making me more
> uncomfortable. . . . When someone doesn't look away, like this guy, then it's
> harder to read it as just [she makes a sound like laughter, not laughter born of joy
> or humor, but rather sarcasm or cynicism] innocent, quote unquote, curiosity.

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some people with dis/abilities do not get adequate mirroring in childhood and long to be noticed, being the
object of "scrutiny" or "the stare" is semantics when one is that object. To the extent that there may be a
difference, one place to look is in the mind of the onlooker and not only the psyche of the one feeling (or
being) stared at.

<div style="text-align:center">181</div>

Rebecca recognizes patterns in people's staring habits. Most typical, in her experience, is for people to stare until she catches them staring. Then they look away, which she attributes to embarrassment. But she observes that they cannot quite keep themselves from staring, so they repeat this pattern of looking and looking away. She interprets this dynamic as curiosity—they are wondering what happened to her and want to learn about her. It is interesting that Rebecca has taken in as much as she has about the stares she has experienced, because early in our interview she reported that stares are so common and happen so often that most are not at all significant. "I'm really more aware of them on a subconscious level, because they're so common. It's really not something I think about." So we have a paradox—Rebecca is both aware of stares enough to identify and interpret patterns, and she does not always think about them because to do so would interfere with her immediate tasks and her life.

How might this "aware-not aware" dynamic be related to mirroring? To take them all in as a picture of who she is, as a reflection of herself, would be overwhelming and misguided. But to be aware at some level, yet also to keep her distance from them, allows her to remember who she really is, to remember the picture of herself internalized from childhood and reinforced through subsequent interactions with significant others—a wonderful person with specific gifts and abilities and certain limitations.

When the man on the street fails to break the stare, as most people do, Rebecca begins to doubt that this is "'innocent' curiosity" and suspects that its meaning lies somewhere else. His continued staring makes her uncomfortable. He is not following the pattern that has become most familiar and benign to her. There is an invasiveness about his unbroken staring, which continues in the next part of the encounter. It is not

only that it does not follow the typical pattern where people realize that their staring is something about which to be embarrassed. It asserts a power differential—he feels he has the right to stare, and so he stares. He seems to feel no compunction about this.

Scene 3: "He thought he had said nothing wrong"

> So anyway I get closer to him and he says "Hello" and I say "Hello." I don't stop—my intention is to just keep going past him. But then he says, "What happened to you?" And I say, "I was in a car accident; my car exploded in flames." I just sort of respond and still intend to keep going. . . . So, as I'm moving towards him, I'm answering those two questions. Then he says, "Are you able to do anything, do you have a job, or are you able to go to school, or anything like that?" About this time I'm actually right next to him, and so I stop to respond to that question—probably because I feel like I need to educate him and say: yes, I am capable of doing something. So I say, "Yes I'm in school, I'm a student." And he says, "Oh, that's good. I'm glad to hear that." So for a moment I think: oh, I've misread this guy; he's actually just interested and supportive—but just for a moment, because then he says, "Well I'm glad to hear that, because it sure is horrible to have to look at you. You are horrible to have to look at. I'm glad that you are able to do something." Then I really did stop in my tracks. I mean, how do you respond to that? So I'm pretty sure I just looked at him blankly. And then he said something, I can't remember exactly what he said, but something to imply that he did not think he had just said something inappropriate—sort of like "well, have a nice day" or "good luck with your studies" or something very flip so it became clear to me that he thought he had said nothing wrong, what he said was completely justifiable.

Rebecca discovers the picture this man has of her and mirrors to her through the comments that accompany his staring. Though a stranger on the street, he asks her personal questions ("What happened to you?" "Are you able to do anything?"). He questions her abilities ("Do you have a job or are you able to go to school or anything like that?"). Unsolicited, he tells her his view of her appearance ("You are horrible to look at."). Like failed mirroring, he reflects a distorted picture of Rebecca. The image he mirrors is not Rebecca but cultural views of dis/ability—exaggerated inability and unsightly appearance.

His comments have implications beyond this particular incident with Rebecca. To people with noticeable dis/abilities, it is not a trivial matter to be assigned visual unpleasantness or deviance. There was a time in the history of the United States when people deemed "unsightly" were kept out of public view—by law.[39] Even today, after the repeal of such laws, occasionally an advice column will publish letters by people complaining that their dinners or appetites were ruined because seated at a nearby table was a person with an obvious dis/ability whose eating style did not meet the standards of the letter-writers.[40]

Social ranking according to personal physical characteristics places nondisabled people higher than people with dis/abilities. Murphy notes that, when he began using a chair, his status dropped. Many of his peers at the university where he taught avoided him, while graduate students, people of color, and women were more welcoming and open to him than they had been before.[41] The nondisabled person assumes she or he has the privilege of abridging social norms of conduct and, thus, can ask intrusive questions or behave in invasive ways. This is also traditionally true of men interacting with women. It is a matter of power dynamics. Reciprocal treatment is reserved for peers. People with higher social status regularly break social conventions when interacting with persons considered to be of a lesser status. For example, adults may believe it to be their prerogative to question or scold any child, whereas they would rarely behave in that way toward an adult of "equal" social status. That a power differential exists in the mind of the man on the street fits with Rebecca's conclusion that this man "thought he had said

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[39] See Chapter 4, 107, for an example of what are commonly referred to as "ugly" laws.
[40] Govig, 19-20.
[41] Murphy, 91, 126-28.

nothing wrong" and that his actions were "justifiable." Erving Goffman speaks of

"invasions of privacy" felt by a stigmatized person and refers to being the object of

staring as an example. In the same light he notes that "strangers may feel free to strike up

[conversations] with [the stigmatized person], conversations in which [strangers] express

what [the stigmatized person] thinks to be morbid curiosity about his condition."[42]

Goffman continues: "[t]he implication of these overtures is that the stigmatized

individual is a person who can be approached by strangers at will, providing only that

they are sympathetic to the plight of persons of his kind."[43] There does seem to be an

implication on the part of strangers that people with dis/abilities can be approached at the

strangers' discretion without any regard to the wishes of the person with a dis/ability.

The opinions of the man who initiated a conversation with Rebecca were

unwanted, but not because he failed to show sympathy. In fact, Rebecca later said,

stressing that she really does not know what he thought, "he might have thought he had

done a good deed by talking to this little crippled girl and encouraging her in her studies."

Sympathy is not the point. She experienced him as unusually rude. "It's not in my daily

reality that people are so rude." This staring encounter was invasive, involved power

dynamics, was experienced as devaluing to Rebecca, focused on what Rebecca's

impairments conjured up in his mind, and reflected an inaccurate perception of who

Rebecca is.

<div align="center">Scene 4: "Stunned"</div>

> I'm still stunned but it's clear that the conversation is over from his position and I
> don't really want to be with this guy anymore so I take off but by the time I go
> about a block I'm just really shaken and I can't decide, I don't mean

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[42] Goffman, 16.
[43] Goffman, 16.

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intellectually, but my emotions can't decide whether to cry or to laugh because it's so absurd that someone would just come up to a stranger and say something like that and not think it was rude. So I think that because I was on my way to somewhere I didn't cry and I just tried to [think]: whatever—that guy's an idiot. But later when I got home I did cry about it because I think it just finally hit me that that is how some people see me. Rude or not, that's how that guy saw me. I think what happens with conversations like that is then all the other daily stares that had happened that day or that week, all of a sudden they all mean exactly the same thing. And so it takes time to get over that and to go back to this place of [thinking] maybe they're just staring because they're trying to figure me out. No, they're staring at me because I'm so horrible to look at.

Encountering the stare is damaging. It shakes up Rebecca. She is not sure whether to cry at the hurt that is inflicted or to laugh at the absurdity of the stranger's actions. But the damage is more than the confusion it causes. The damage goes to the core of her psyche-soul-body-self. It is traumatizing, and she re-lives it for a while when she finds herself confronted with other stares. Not every staring event hits her as hard as this one did. Later she described another incident where she laughed at the person accusing her of something she considered ridiculous. She said she could laugh that time "because there's no part of me that believes it." Regarding the incident above, however, she reflects that his "comment hits me because there is a part of me that believes that I'm horrible to look at." Besides being hurt by his thoughtless comments, Rebecca was unsettled and aggrieved by an inner wound, which his remarks brought to the surface and re-opened. She looked into the mirror of his face and saw both his image of her and an internalized distortion. Failed mirroring damages one's ability to know oneself accurately, and so it took her some time before she was able to recognize the distortion in the mirror. It is important to emphasize that Rebecca does not stay with the negative cultural value for long. The thought that everyone who stares is making a value judgment

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eventually gives way to her typical pattern of imagining that others wonder what happened to her and how she does what she does.

The devaluing stare has an impact that can throw one off balance, can discount and annihilate the person one is, and damage one's own confidence in and knowledge of self. The devaluing stare wounds but, thankfully, it is not the only relational experience in the lives of most women with dis/abilities.

Restorative Relationships

In Chapter 1, I noted that travelers in medieval times utilized mirrors as a strategy to protect themselves from the basilisk's deadly stare. Similarly, reasonably accurate mirroring relationships protect people with dis/abilities from the potentially harmful effects of the devaluing stare of strangers. Many women with dis/abilities have friends and family members who offer restorative and affirming relationships, filled with adequate mirroring. Rebecca notes the contrast between the way the man on the street regarded her and the way others who know her see her.

> I think—obviously this man would disagree—but I think in a lot of ways I'm very blessed. I have a supportive family who cares about me, and I have really good friends, and I have a partner, and *that's not the image I have reflected back, the image that that guy saw is not the same image that they give me or that I see in their eyes* [emphasis added].

Among the vital characteristics of mutually affirming and empowering relationships is a sense of self worth.[44] Rebecca knows herself from the picture she sees in the eyes of those who care about her, and she knows she is valued by them, thus providing a view of herself contrary to the one presented by the stranger on the street.

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[44] A sense of worth is one of five characteristics identified as contributing to mutually empathic and empowering relationships by Jean Baker Miller and Irene Pierce Stiver in *The Healing Connection* (Boston: Beacon Press, 1997), 30-34. The other ones are zest, action, greater knowledge of self and others, and greater connectedness with others.

In mutual, affirming relationships, the "good enough" mirroring, empathy, and empowerment is reciprocal. The caring moves in both directions. Therefore, not only has Rebecca been blessed by mutually empathic, liberating, and caring relationships, others have been blessed by their relationship with her. Women with dis/abilities are mirroring to those around them as well as receiving from others. Mutual and restorative relationships can happen with family, friends, and communities, including communities of faith. Therefore, the potential exists for nondisabled people who are open to the healing power of a mutually restorative relationship to be transformed by people with dis/abilities mirroring the best of the nondisabled self.

The Mirroring Face of the Holy

The benefits of adequate mirroring and the deficiencies of inaccurate mirroring are laid down in infancy and childhood, but the consequences extend beyond the early years of life. Images of God, which are formed during childhood, have their foundations in interactions with a parent or other significant persons in a child's life. Damaging interactions with a primary caregiver in childhood are represented in the God images of adults.[45] Ann Belford Ulanov states that our sources for imaging God also include faith tradition, personal experience, and the "unfathomable mystery of God."[46] If adult God-images relate to human mirroring and cultural influences, negative interpersonal encounters with attitudinal barriers, such as we find in the stare, may have an effect on a woman's understanding of the Divine and her relationship with a faith community.

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[45] Rizzuto, *The Birth of the Living God.*

[46] Ann Belford Ulanov, *Finding Space: Winnicott, God, and Psychic Reality* (Louisville: Westminster John Knox Press, 2001), 21.

The mirroring face of God as presented in some dis/ability studies literature is neither adequate, accurate, nor loving. Bill Hughes portrays an exceedingly harsh image of the God of the Jewish and Christian faiths as revealed in their sacred texts. He accuses the "oppressive gaze" of God of creating people with dis/abilities as grotesque and sinful. "The multiple constitutive power of the ocular is, perhaps, at its most telling and negative in the annals of the Judeo-Christian religions in which the gaze of God—in testaments old and new—gives testimony to the monstrosity and sinfulness of impairment."[47]

Hughes supports his claims through reference to an essay by Avi Rose.[48] Rose's essay discusses some of the problematic beliefs, texts, and traditions that the Jewish and Christian faiths have regarding dis/ability. Rose rightly identifies components within the Jewish and Christian traditions that have presented dis/ability in negative ways. "These are disability as sign of punishment or evil incarnation; disability as challenge to divine perfection; disability as object of pity and charity; and disability as incompetence and exemption from religious practice."[49] He also acknowledges the impact such beliefs have had on the larger society, to the disadvantage of people with dis/abilities.[50]

Nonetheless, Rose argues there are "deeper core beliefs" which "compel" the Jewish and Christian faiths to uproot religious prejudices toward people with dis/abilities. These "deeper core beliefs" are "the ideals of inclusion and acceptance, the glorification of divine creation in its many forms and a striving for the betterment of humanity."[51] Rose recognizes an alternative narrative within the sacred texts and congregational life.

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[47] Hughes, 163.
[48] Avi Rose, "Who Causes the Blind to See," *Disability and Society* 12, no. 3 (1997): 395-405. Hughes' indictment against the gaze of God is stronger than the Rose essay as a whole warrants.
[49] Rose, 397.
[50] Rose, 397.
[51] Rose, 403.

Joanne and Camille are currently engaged in communities of faith. Neither of them saw grotesque, sinful creatures in the mirroring face of God. Camille thought God saw her as "perfectly imperfect." In a mirroring relationship, the person who mirrors communicates both appreciation for the other and fairly accurate perceptions of the other's abilities and limitations. One might say the mirroring individual communicates that the other is "perfectly imperfect"—loved as she is with her physical, emotional, cognitive, and spiritual particularities.

Joanne does not believe the gaze of God finds her wanting. "I know he understands everything. I don't think he sees me as a disabled person. . . . I don't think he sees me as not being equal to another person." Joanne believes that God sees and understands all the difficulties in her life—the times when she has been stared at, ignored, rejected, or dismissed and the hurt that she feels from such situations. The mirroring face of God does not reflect a "lesser-than" person nor someone whose dis/ability sets her apart in a negative way. The Holy One sees a person who is as embraced by divine love as is every other person. Joanne believes she is a woman who is loved, understood, cared for, and completely accepted by God. In her poetry, Joanne portrays certain persons reflecting God's love to her and she mirroring Christ to others.[52]

Edie, Liz, and Rebecca grew up affiliated with mainline Protestant churches but have discontinued this association. Edie has turned to Buddhism to nurture her spirituality and finds it to be more in tune than Christianity with her natural beliefs. Buddhism seems to mirror more clearly Edie's person and values. Liz indicated that spirituality is important to her but attends to this aspect of her life privately. In part, the

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[52] Joanne writes "The joy in my eyes/Reflecting Your love" in a poem called "Salt and Light" found in her booklet, "My Father's Vessel."

physical discomfort of sitting through a worship service interferes with her attendance, though what she perceives as discrepancies between the church's words and actions disturbs her as much. Even as a child, she recognized inconsistencies between the inclusive relationships Jesus had with others and the physical barriers that restricted the full participation of people with dis/abilities in her congregation. The Jesus she knew was not the Jesus who was mirrored to her by her church.

Rebecca states that she does not consider herself Christian anymore. Her theological disagreements with the church are multiple. In addition to her rejection of her congregation's positions on women and homosexuality, her primary reason for distancing herself from Christianity, she is uncomfortable with the ways that religious people "read" her and her impairments and project their religious beliefs onto her. Rebecca becomes a mirror for their fantasies. She does not want "to be around people who are going to read me . . . [and] use me for their religious purposes."

The lived experience of women with dis/abilities demonstrates that cultural assumptions, mirrored through the stare, wound by their dismemberment and narrow interpretation of what is seen. Attentiveness to the religious and other cultural contexts could tell a listening church that the construction of representations, which are inaccurate, incomplete, and fail to mirror the individual herself, diminish a part of God's creation.

Listening to the narratives and voices of women and men with dis/abilities is a prerequisite for revisioning theological concepts and pastoral practices in light of the experience of living with a dis/ability. Theological reflection includes a personal examination of the ways pastoral theologians and persons involved in pastoral practice have accepted, and acted on the basis of, cultural assumptions. Women and men with

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dis/abilities have already begun to work for change. Pastoral theology and practice involves joining people with dis/abilities in the resistance to devaluing beliefs and interactions. Claiming stories that show the loving, mirroring face of God offer an alternative to a God with an oppressive gaze toward persons with dis/abilities.

Theologian Elisabeth Moltmann-Wendel presents a God who gazes at us lovingly when she quotes from a sermon by Rabbi Margaret Moers Wenig: "God takes our face in both her hands and whispers. . . 'Even when you are old I will be with you and hold you when you are grey-haired. I have given birth to you, I carried you, I will hold you fast.'"[53] Granted, neither Rabbi Wenig nor Moltmann-Wendel are speaking specifically of people with dis/abilities. They are referring to people, especially women, who are growing old. Though women and men with dis/abilities and elderly women have had different assumptions made about them, neither group has been immune from being portrayed in a negative light. Yet, Wenig imagines God taking our faces in her hands and promising steadfast presence and care. This is the type of gaze that most resembles what we experience in the face of adequate mirroring. Correspondingly, it is the gaze that exemplifies affirming and restorative relationships. It is the opposite of the stare. Ministries of care with an eye to liberating practice and prophetic witness offer the possibility of a pastoral practice which challenges the dominant cultural view by treating

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[53] Moltmann-Wendel, 33. No reference was given. I am grateful to my daughter, Katie Ricks, for finding a copy of the sermon and passing it along to me. See Rabbi Margaret Moers Wenig, "God Is a Woman and She Is Growing Older: On God," in *The Book of Women's Sermons: Hearing God in Each Other's Voices*, ed. E. Lee Hancock (New York: Riverhead Books, 1999), 255-61. The lines quoted can be found on 259-60.

people with the same dignity, care, and respect that the God of Camille, Joanne, and

Rabbi Wenig assigns to all people.[54]

This chapter described the psychoanalytic concepts of mirroring and failed

mirroring and applied them to the interpersonal interaction of a staring encounter. The

following chapter zooms in on staring encounters by analyzing more closely the internal

dynamics experienced by women with dis/abilities who have been the object of the stare.

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[54] Andrew D. Lester, *Hope in Pastoral Care and Counseling* (Louisville: Westminster John Knox Press, 1995), 1, suggests liberating as a fifth pastoral function in addition to the traditional four—healing, guiding, sustaining, and reconciling. Professor William M. Clements, Claremont School of Theology, suggests the fifth function of pastoral practice is a prophetic one.

CHAPTER 7

ENCOUNTERING THE STARE: INTERNAL DYNAMICS

In the stare as failed mirroring, the person who stares reflects to the one stared at

an inaccurate picture of herself. Internal reactions inevitably arise in the one stared at.

The women I interviewed report at least three internal dynamics connected to staring

encounters: (1) clashing realities, (2) internalized ableism, and (3) inner protest.

The internal dynamics I describe are fluid and flow into one another. They are

difficult to separate. They are not like strands of yarn that can, theoretically at least, be

untwisted. They are more like green food coloring—blue and yellow dyes are in there,

but neither can be separately retrieved. So, too, with internal dynamics. We can identify

some dynamics at work, but they are intertwined so that when emphasizing one, the

others get in the picture too.

Clashing Realities

An awareness by women with dis/abilities of clashing realities involves the

realization that in a particular interpersonal interaction, one's own perspective and the

other person's perceptions not only do not match but collide. This is a different

phenomenon from two people experiencing the same event and seeing or remembering

different elements of it. It is more than a difference of opinion between two people about

what happened, and when, where, how, and to whom. This collision is disconcerting and

startling, and the consequences can be dangerous, demeaning, or devaluing. Thus, in the

interaction between Rebecca and the man on the street in the previous chapter, she is

"shaken" and "stopped in her tracks," not only because he doubts her abilities and insults

her appearance, but also because his understanding of dis/ability and her experience were

at odds. One party involved in the collision of realities is aware of the clash, and the other one usually is not. The result is not necessarily benign. Edie concludes that the nondisabled person whose reality conflicts with hers is "dangerous." If that person is in a position of authority, such as the medical professionals entrusted with Edie's care, the risk for Edie is that she may become further disabled by actions taken as a result of that person's misperceptions.

Returning to the illustration of distorting mirrors in a funhouse, it is as if the culture believes that the images seen in the mirror—the distortions—are reality, whereas the woman with dis/abilities knows that her experience of reality clashes with the distorted reflections. When distortions are communicated and/or perceived as reflecting the world as it is, funhouse mirrors are no longer amusing. The person with a dis/ability can end up having the sense of living in a parallel universe that overlaps but is incongruent with the world of the other—the perceptions of reality clash and collide. In one universe, the distortions are viewed as reality. In the other world, a separate reality is experienced by the individual whose image is reflected back inaccurately. The woman with a dis/ability knows a truth that rests in, through, and around her, and she also knows the representations and expectations that culture carries. Both are a part of her knowledge.

One consequence of colliding realities is that it can be difficult to stay grounded in what one knows for one's self when clashing with a perception that calls one's own reality into question. When the impact of the clashing realities hits a woman with a dis/ability, she can feel shock and disbelief and experience life as surreal, as if one were

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living in the twilight zone. Colliding with a distorted perception of reality can be traumatizing.

Joanne reported a number of incidents of clashing realities. The following occurred on a city bus when she was in her late teens:

> It was the first time [I was] on a RTD bus. I went with a friend from my dorm. We were going to another friend's house one evening. We went to McDonald's [earlier], and we had a shake in our hands. And we got on the back of [the] bus, facing each other—I guess I was facing everyone else. So we were just talking—you know, how we talk and how I get excited—just talking and having a great time, just talking [and] talking. *And all of a sudden,* I'm just looking at everyone on the bus, and it's like everyone just [was] turning around and just looked at me. And so I said, "'Pat,' why is everyone looking at me?" And she just said, "'Cause they think you're drunk." That was the first time I ever heard that, and so I was laughing and crying at the same time, because I was just in *shock.* Then, the bus driver came back and asked me to get off the bus. It was the most embarrassing; it was so embarrassing. [She now speaks very softly, just above a whisper.] And it was just really embarrassing.

In this episode, Joanne is in college and venturing out on the bus for the first time. She is doing what any other college student might do—going with one friend to visit another friend, complete with a McDonald's milkshake in hand. She is having a good time, paying no attention to the other passengers, totally engaged in lively conversation. Life is good, and she is being herself. She is comfortable with herself and with her friend. Then—smack!—she comes face to face with a reality that collides with her understanding of herself and her being in the world. Her joy melts into pain. Her fellow passengers do not see a typical, talkative, shake-drinking college student on her way to a friend's house. They do not even see a young woman with a dis/ability who exhibits

some typical features of that dis/ability. They "see," at least according to her friend's interpretation, a person who is drunk.[1]

Even though Joanne had experienced mistreatment at the hands of nondisabled children and adults throughout her life, she was unprepared for this moment. She was and is shocked by this experience. As she spoke the word "drunk," her shock was palpable, as if she were reliving that feeling and event once again. Her disbelief at the clashing of her reality with the other passengers' and the bus driver's reality came with additional reactions. The thought of others viewing her as drunk was preposterous and horrifying. Being misjudged and put off the bus was shameful. Joanne was confronted with the task of dealing with conflicting perceptions and also with the embarrassment of being mischaracterized and seen as transgressing cultural rules.

This was a powerfully negative incident for Joanne. A staring event like this often requires a caring response, if the episode is not to become ingrained as a characteristic of the woman herself. Since the putting her off the bus was dictated by persons with a distorted reality, it can be helpful if a caregiver names and identifies the experience as one of clashing realities. The people on the bus lacked knowledge about dis/ability and misinterpreted the situation. Their actions were wrong. Joanne did nothing to deserve the mistreatment she received. The bus driver and passengers' lack of knowledge and their inappropriate action reflect on them—not on Joanne.

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[1] Sociologist Erving Goffman, writing a decade before this event likely took place, places both persons with visible physical dis/abilities and those who struggle with alcoholism in the same category. They are persons marked by a stigma and characterized as deviant. See Erving Goffman, *Stigma* (Englewood Cliffs, N.J.: Prentice Hall, 1963), 4. Interestingly, comedian Geri Jewell who appeared occasionally on the NBC television show "Facts of Life" once wore a T-shirt that read "I'm not drunk—I have cerebral palsy."

Unfortunately, Joanne bears the wounds of another's ignorance. For some people, healing comes from telling the story of the injustice. In this case, the caregiver might suggest writing a letter to the bus company to express the hurt and injustice as well as to educate others about dis/ability. Another avenue of care and healing could be to remember times when, unlike the painful bus incident, the woman was known well and accepted.

A woman can determine what weight she will give to harmful encounters in her life experience. At first, an incident such as this will likely weigh heavily in one's personal narrative. This is what happened with Rebecca and the man on the street. It took Rebecca some time before she could put it in perspective with all her relationships. A painful encounter can be mourned for all the hurt and power it carries. Eventually, with care for self and by others, a woman can weave the incident into the background of her life, rather than the forefront of her memories. Then, the incident can be something that happened to her in the past, rather than something that defines her today.

At the time of the bus incident, Joanne did not have a supportive family nor a community of friends sensitive to a social political perspective of dis/ability. The support for putting acts of discrimination in perspective was not available to her, or to many others, at that time. It is more difficult to reweave one's personal narrative decades after damaging events. But it is not impossible. Pastoral counselors and other mental health professionals can help facilitate this kind of healing if and when it is desired.

Edie experienced clashing realities, especially related to her potential and actual abilities. As Edie understands it, the stare is related, in part, to people's surprise at her abilities. The very word "disabled," in the way it is commonly used, emphasizes

inability. It is frequently used to refer to something that is broken down, for example, a "disabled vehicle." The perceptions of the nondisabled world clash with the known abilities of women with dis/abilities. Edie explains that people in general seem to have low expectations of her, physically and intellectually. This is not atypical. Dis/ability is often universalized. Dis/ability is all that is seen, and it is taken for granted that it encompasses all features of an individual.

The expectation of inability by the nondisabled population results in people offering Edie "help" in a multitude of ways when it is not needed, such as filling out forms, retrieving her change as the coins roll down automatically from the cash register, and maneuvering her chair in and out of her car. Others' surprise at her abilities clashes with her daily living experience and her self-expectations. This collision of realities between her and others leads to another internal clash. Edie experiences some of these offers to help as "insulting." At the same time, she has a philosophy of life that finds helping one another a good thing. Therefore, "I don't take offense. . . . If someone's offering help, they have good intentions. . . . They're thinking: 'That's somebody who could probably use a hand and I'm going to offer it.' But that's not always the best thing to do." Conflicting realities may result in persons who might lend a helping hand not being helpful at all and sometimes even disruptive.

The medicalized gaze, as a variation of the stare, evaluates what is "wrong" with or "abnormal" about a particular body. In Edie's opinion, the medical community is just as likely to have misconceptions about her abilities as the general population. Prior to our interview, she had spent a month in the hospital due to a decubitus ulcer (a type of skin sore). She found the medical personnel to be helpful and caring people. However,

her own sense of what she was and was not able to do clashed with theirs. The message she heard over and over again was, "You can't do it." Reflecting on her hospital stay, Edie states that "I learned all over again, in many ways more deeply, how insidious and how disabling that experience itself is—being told 'You can't do it.' . . . My activity was very restricted, and they were really treating me with just a little too much caution."

Though she trusted that her caregivers had good intentions, that is, they were invested in her wound healing, she believes the methods used to carry out their intentions were misguided. "I got to know the nurses. They were nice. They were caring. They were sweet. They wanted to do things for me. They wanted to help me—but that was dangerous." Edie is not only trying to negotiate clashes between her reality and that of her doctors and nurses but also between feeling threatened by restrictive medical recommendations and feeling kindly toward the staff's expressions of concern while needing *some* medical help. She experienced many of the medical personnel's offers of help and suggestions for special equipment as "dangerous, really dangerous," because those offers and suggestions underestimated her capabilities and, if enacted, would have made her more dependent than she feels she needs to be.

> All those people there, they had good intentions. They wanted things to be easier for me. They wanted my wound to heal as quickly as possible. They wanted good things—their intentions were for good, but the effects, if they had been able to carry out what they thought needed to be done, if they had succeeded with their intended actions, that would have been bad—it would have been very bad. . . . I would have been further disabled—I would have been unabled. . . . Those things [the suggested equipment] are inconvenient, but worse than the inconvenience of those would have been the idea that I needed them, the deeper feeling of dependence on those things and less feeling of independence, of capability. That's so much more valuable than anybody realizes. . . . My desire for independence . . . gives me a feeling of . . . reassurance that I deserve to be treated like a person. . . . It's important for me to feel strong and to feel that I show strength and independence. . . . There's something about that that is not very

nice—the idea of somebody looking at me as somebody weak, somebody dependent, somebody that they need to help a lot.

To have others see and respect her capabilities, rather than assuming inability and need, is important to Edie. This is not to say she is unappreciative of help. When she needs help, she accepts it willingly and gratefully. However, she strongly believes that to accept help for something that she is capable of doing herself does a disservice to both the other person and to her, and to become dependent upon gadgets she really does not need is further disabling. She is confident about her abilities. She enjoys using her body to the fullest. This perspective often clashes with the perceptions of nondisabled people—medical professionals and strangers on the street.

Included in clashing realities are the differing narratives Edie and the medical community had about the way she should live her life. The medical professionals focused their understanding of her needs and life choices on her susceptibility to the reoccurrence of decubitus ulcers. They recommended assistants to help Edie with some of life's daily activities and special equipment, including a cart that would allow her to maneuver herself around her apartment face down. Edie, on the other hand, did not want help with chores she already performed, and she did not want to live even part of her day face down on a rolling cart. She would rather take the risk of another decubitus ulcer than live in a manner that did not fit her.

In addition, she is suspicious of people telling her that she needs medical equipment that she has, heretofore, done quite well without. She concluded that such things would have made her more disabled, would have increased her inability, and that she resented and resisted. She had to resist mightily, because the full force and authority of the medical community pressured her to live into their narrative of the life of a

paraplegic. Persons involved in ministries of care can assist a woman who is in a situation similar to Edie's by encouraging her to identify the differences between the cultural or medical narrative and her life. Appropriate care may involve supporting a woman's resistance to a life narrative crafted by someone else.

As noted in chapter 3, Camille told a series of narratives in which persons staring at her misinterpreted her neck spasms and accompanying head movements. As with the other women, Camille found herself in a situation where the reality of other folks clashed with hers. To Camille, the particularities of her body are a private matter—not a matter of public scrutiny, conversation, or ridicule. When others focus and comment on her body or a part of her body, she experiences it as an intrusion into her personal space. It is personal—it is her body that the strangers are concerned about, talk about, laugh at, or mock. Paradoxically, it is also impersonal—none of these people are interested in Camille as a person. Their eyes and attitudes are focused on a part of her and caught up in their own frame of reference. One thinks she is in a medical crisis. Another finds her movements amusing and wonders how she does it. The third one taunts her by imitating her physical motions in an exaggerated way. They are not interested in or even seeing Camille. Their anxiety, humor, or hostility takes over. Camille is demoralized by these clashes.

What are some options for effective care for women like Camille when they become discouraged by the focus on their bodies? For some women, it is helpful to have a place to be able to express their dislike, frustration, discouragement, and anger over intrusions into their personal space, a place where they are heard and not dismissed or doubted, a place to mourn the reality of the stare and the implications of it. It may be

helpful to have someone who can acknowledge that some people are largely intolerant of diverse bodily movements and configurations, and that these experiences of intrusion and/or marginalization do happen and will happen again, at another time, in another form.

Effective care also allows other stories to emerge, stories when an individual is seen intact, as a whole person with many characteristics, only one of which has anything to do with dis/ability. To be able to celebrate the absence of discrimination is as important as mourning its existence. Life is a mosaic—mourning and rejoicing are both parts of the pattern. At different times, one may be more prominent than the other, but both are part of the design.

Internalized Ableism

Internalized ableism is the process and result of taking in, making part of oneself, and judging oneself by, cultural views of what is designated as physical ability and labeled "normal," good, and right versus what is assigned as dis/ability and called lack of ability, abnormal, bad, and wrong. It occurs when a woman with a dis/ability internalizes—sees herself—with society's eyes. She may believe society's images and representations about her or become extra conscious of what others are seeing in and assuming about her. When, following an encounter with the stare, one's internal processes emphasize one's self as "other" or one's thoughts are absorbed by a self-consciousness about one's appearance, internalized ableism has risen to the surface and claims a hold on self-perception.

Internalized ableism is a form of internalized oppression.[2] It grows out of socialization in a culture that places a high priority on approximating an ideal body.

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[2] Internalized oppression could also be internalized racism, internalized sexism, internalized heterosexism, and so on. Internalized ableism is internalized oppression with an ableist content.

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Contemporary culture teaches women to desire the perfect body and to seek it at an extremely high cost—physically, financially, psychologically, and spiritually. Those whose bodies differ in a significant and noticeable way and are subject to culture's disapproval and denigration internalize society's values as everyone else does. Internalized ableism is a way to name this inculcation of society's ableist's views.

Rebecca describes an experience of internalized ableism as she explains what happens at a feeling and thinking level when she encounters a "significant staring event" or when the common daily stares "build up." A single incident of the stare that is not accompanied by comments from the person who stares, "everyday occurrences" for Rebecca, can be ignored. But "once there's enough of them, then all of a sudden I have to deal with them." Part of dealing with them involves facing what gets stirred up internally.

> Well, I feel very abnormal, very aware of the fact that I'm not "normal" (she gestures to put this word in quotation marks). And at that moment when I'm feeling that way and thinking about these times people have stared at me, at that moment I forget that I really do lead a relatively normal life and that I have friends; I leave my house; I go do things on my own; I have a job; and I'm a student, which almost counts as a job. But, when I'm depressed, I forget all of that. I'm this really abnormal strange-looking freak-person who can't do anything, which is a description that isn't really borne out by my daily life—but that's how I read the stares. And when they build up I start to believe that picture of myself. I never believe it for very long, because either I can't cry anymore—I'm out of tears, or the phone rings, or I have to start my life again. Once I start my life again, then I'm no longer this person who can't do anything but be a freak who's stared at. I would say that's probably the most common reaction or response I have in terms of the stare [when] I reach a crisis point. But that also happens a lot less than it used to. I think the stare, the daily, everyday stare used to bother me a lot more my first year or two after my injury. . . . The first couple years I think that it was really maybe once a week where I would really have to just sit down and cry. Now it's probably less than once a month.

Rebecca occasionally reaches the point where she has to deal with accumulated incidents of being the object of stares or when one of these events is so shocking due to

verbal comments accompanying the look. When this happens, internalized ableism is the result. The cultural representations of women with dis/abilities take over her own understanding of herself. She views herself as an oddity, who is marked by inability, and whose only use in life is as the target for another's eyeballs. She sees herself as not fitting within the bounds of what is considered "normal." This abnormality has something to do with her appearance, which she now describes as "strange-looking." In fact, she feels so strange as to be a "freak-person." This is a very powerful symbol for people with dis/abilities. As noted in chapter 4, "freak shows" used to be a form of popular entertainment in the United States and elsewhere. When Rebecca reaches this crisis point, she relives the past and re-presents cultural views of people with dis/abilities.

Fortunately, this is not a permanent condition. It is a form of temporary amnesia. For a short period of time, she forgets the totality of who she is and what her life is like. She temporarily forgets the greater part of her personal history, and the content she does remember is the accentuated difference that has been stirred up by others. For Rebecca, the internalized ableism is short-lived. It is powerful and overwhelming when it comes, driving out all other perspectives. It is recurring, but the frequency of these bouts lessens over time.

Embedded within Rebecca's narrative are the steps that take her into and out of internalized ableism. First, she sees dis/ability from another's perspective, and she mourns that she is that person. Then, some event or task interrupts her grief, and she becomes involved with her regular activities. Once again she realizes that she is not at all the person that the stranger saw her to be. Rebecca can identify this progression in retrospect. One important dimension to caring that we can learn from her narrative is to

watch for a healing pattern that a particular person may have within them. Sometimes the task of a pastoral caregiver is to assist a woman in noticing her own way of healing from discriminatory circumstances. Then, in time, it may become possible for that woman to utilize what she knows about herself to care for herself and/or to work with someone else in her process of healing from confrontations with devaluation.

Internalized ableism can be triggered by a stare with commentary, as in Rebecca's narrative above. It can also be triggered by the stare itself. That is, when a woman begins to experience someone staring at her, she can begin to see herself, to evaluate herself, through the eyes of society, to become so self-conscious of society's evaluation as to lose her own knowledge of herself. The activation of internalized ableism does not require the words of another; she may supply them herself. Often a woman is right about what the stare means in a particular instance, her conclusions having been borne out by so many previous stares and comments, but not always. Camille tells the following story "on herself," in which she associates herself mainly with her dis/ability when the onlookers have not.

> I was sitting in a restaurant and I was reading and eating lunch. [At that time] I had hair down my back—I had really, really long hair. And these two women were staring at me and I thought "Oh great, they going to make a comment about my neck spasm or something." So I was trying to prepare myself for what they were going to say and how I was going to react. And I was trying to read at the same time and just do what I was doing. And then all of a sudden, one of the women said "I'm so sorry we're staring. I'm so sorry we're staring at you, but you have the most beautiful hair I've ever seen." And I was *so* prepared for the other. But, it just showed me that you just never know what people are going to say or what people are going to do. . . . I was so humbled by it. That's the best one [story of the stare]. . . . Somebody saw beyond the head movement. To me, most of the time I don't focus on it, and I just go about my business, but then there are people—I think it depends on how far can they see. . . . I mean it's like some people can only see the surface. Some people I think can see beyond that and it's not a big deal. And I was the one that was only seeing that they must just

be seeing the surface. . . . And I was wrong. That was just the nicest one ever and the one I like to remember above all the other ones.

Camille delights that she was wrong. It is very important for Camille to remember that some people can see something in her other than her dis/ability. She has come to associate people staring at her with people noticing only her dis/ability and, indeed, this is the only narrative of the stare that she tells where her dis/ability was not the focus.

It may seem unusual to include this narrative of an act of staring unassociated with dis/ability and devaluation in a work highlighting those connections. This story belongs in this category of internalized ableism, because that is the way Camille experienced and described it. When she became aware that the women were staring at her, she began to plot her strategies, imagining what they would say about her neck spasms and planning how she would respond. In fact, she was so distracted by the staring and her own thoughts that she is unable to do the things she came to do—eat lunch and read. The irony that, in this incident, she alone is most conscious of her dis/ability is not lost on her.

An episode of being the object of the stare can stir up societal values of dis/ability and the memory of previous experiences with the stare. It can bring up the phenomenon of looking at oneself through society's eyes; that is, the stare can provoke internalized ableism. In Camille's case, this incident provided her with a new awareness, because in her previous (and succeeding) experience, the stare has meant judgment, misperception, or mocking. However, if the stare can mean something other than judgment, misperception, and mocking, even infrequently, this opens up the possibility of breaking the connection between cultural views of dis/ability and beliefs about oneself. Severing the link between cultural assumptions about dis/ability and self-perception may be a task

that a woman with a dis/ability would want to work on with a pastoral caregiver or pastoral counselor. Challenging ableism within oneself is an act of creating a personal narrative at odds with the dominant narrative—and believing it.

Inner Protest

Inner protest is the third internal dynamic that emerges from the narratives. Inner protest resists diminishment and affirms one's own sense of self. It prompts a woman to claim her own perceptions about her life and her experiences. Joanne illustrates this when she lists her abilities and accomplishments—"I am a writer and a poet"—and when she insists that others recognize her worth—"I am worthy of being heard"—rather than submit to cultural assumptions and dismissive attitudes toward her. The inner protest argues that one's own perspective, one's own narrative, has a place and must be considered.

Inner protest may take the form of challenging the messages of society that one does not belong or is unacceptable or unimportant. Liz tells of the progression of thought that arises in her when faced with situations of the stare or at times when she is disregarded. Her thoughts begin with a single word, "No." Then, her thought process continues with some variation of "This is not right, and I'm not going to put up with it."

Inner protest challenges distortions that culture mirrors to women with dis/abilities. It refuses to give credence to the inaccurate images of distorting mirrors. It fosters the ability to make choices about one's life work and daily ventures based upon one's inner knowledge of self and not external societal messages.

Rebecca demonstrates how she moves from internalized ableism to inner protest as she describes the changes that take place in her perception following the staring

encounter with the stranger on the street. Directly after the incident, she finds herself in

his frame of reference. As time moves along, "I give myself a reality check." She takes

another look at the whole picture of her life and activities. Her perception is broadened

as she recovers what she knows about herself and her life and is no longer limited by

what the stranger sees and believe.

> That day, when that guy said that thing to me, and . . . the next few days were colored by that comment. Because he was so aggressive, his comment was very clearly, at the time it seemed to be very clearly, about me. It wasn't about him; it was about me—how I am and who I am—and it's really easy to just take those comments in and to feel like there's just something wrong with me. I'm the one who's scarred. I'm the one who's disabled. This is my problem. And no matter what I do in terms of making friends, in terms of finding a job, in terms of having hobbies or whatever, I'm never going to change the fact that I'm scarred and that I'm ugly to look at, and that's just my problem. But I think as time passes, 3 or 4 or 5 or 6 days after I talked to that man, not only do I see different images of myself reflected in people who love me, not only do I find myself involved in activities that mean that I'm not really as pathetic as he made me feel that I am—those two things help me get on with my life—but also . . . [I begin] seeing it not as my problem but as his problem. Okay, yeah, so I may look different from most people, why is that my problem? [His] problem is that [he's someone] who talks too much. And when I can get to that place of remembering that there are a lot of really stupid people in the world, and they're going to be stupid about me or they're going to be stupid about something else, [the problem] is because they're stupid and ignorant and rude. It's really not about me. That helps, too.

Rebecca does two things in this recounting of her inner dynamics: (1) she turns

her initial reactions to the incident "inside out" and (2) she "returns" to herself. She turns

the problem on its head by protesting the stranger's views that the particularities of her

body constitute the problem. She acknowledges that her bodily configuration has some

differences from the majority of the population and challenges the notion that her

difference makes her a problem. In fact, he is a problem, in that he revealed his lack of

knowledge about the lives and capabilities of women with dis/abilities. Furthermore, he

was unusually rude. He is a problem, in that his words ("It sure is horrible to have to look at you") were extremely thoughtless and unkind.

Rebecca recognizes that there are some people in the world who are thoughtless in their speech and ignorant about certain matters. On that day, she encountered one of them. The second thing Rebecca does is recover her memory and experiences of her wholeness and, thereby, her fuller self. She remembers that other people in her life see, and mirror to her, something very different from what the stranger saw. She remembers that she has a full and active life. She comes back to herself and once again trusts her own understanding and assessment of herself and her circumstances. In so doing, she protests the supposition that there is only one way of seeing her life—the way the dominant culture views it—and claims her own perspective. She rejects diminishment—by the stranger's words and by her own thoughts.

For Edie, the stare mirrors the societal expectation of inability. Her narratives about her experience with the medical establishment highlight her determination to claim her own authority over her own body and mind and to protest challenges to her abilities to function in the world on her own terms. Edie engages in inner protest by carefully analyzing the situation she finds herself in and trusting her own life experience and her own values as she comes to a decision about what is best for her. Edie demonstrates the process that goes on in her own mind in the following excerpts from her narrative about her hospital experience.

> It was hard for me to learn, to figure out, what was the right course of action considering my wound, and my health, and everything, and what was just too much caution on their part. Just figuring that out and making the attempt to recognize the difference was an act of independence. That was an assertion of my independence. [They may] know what's right for me physically, by the book, but I know the other part of me. I know my life and I know the things that are going

to work for me. So, it took some time, and some talking myself into it, to trust myself enough to know that what I know about me is as important as what the doctors know about my wound.

Before Edie could respond to the medical community's expectations for her, she had to figure out for herself what was medically necessary to care for her wound and what was right for her life as a whole. She wanted to determine what was right for all of her. She was not willing to base the rest of her life on only a part of her body, though that part, too, needed consideration. She listened to the advice of the medical experts, took into account what she knew about herself, and weighed the two to decide the effects the medical recommendations would have on her life.

As she claimed her authority to make decisions for herself, she ran up against the collective authority of the medical profession.

> But probably even more striking was the realization that a lot of these things they were insisting on doing for me [or] not allowing me to do [were not necessary]. . . They were very, very resistant to [my rejecting their advice] and I began to understand, to see this pattern, and it was filled in with little stories about other people . . . with the same problem—a decubitus ulcer. . . . And some of these stories would indicate that [others have] help doing this. One doctor, in fact my primary doctor, told me that in 27 years of practicing medicine—27 years—(he deals with skin wounds and "decubs,") he had dealt with many paraplegics and quadriplegics and he told me that I was the *only* person in 27 years that he had seen that lived completely independently. And that blew me away. I thought he must be exaggerating at first. I asked him the next day about it. "Are you sure? What are you talking about? What do you mean by that?" Everybody else that he had worked with, that he had cared for, had somebody at least to come and do their grocery shopping, to help them get out of bed, to help them make whatever, had some kind of assistance. So that was really amazing to me. And horribly sad, horribly sad, because I could see how much I had to fight and argue, and how much trust I had to pull out of myself to continue to argue with them, to say, "No, I don't need this help. I don't need anyone." . . . They weren't accustomed to somebody in my position, not only being *able* to take care of herself but arguing [for it]. They were disabling me mentally. Certainly not intentionally—it had a lot to do with the strength of their experiences. But, of course, that's a cycle. The more people that come to believe that they are dependent on the medical establishment, then, of course, the more the medical establishment is needed. So I never really completely understood how that worked until this summer. So in

light of all that, when I do get that stare, I think it has a lot to do with that—surprise that I can do, that I can do.

The medical authority she was resisting could point to years of experience, to stories of people with dis/abilities similar to Edie's who accepted the assistance that was suggested. Her doctor's experience and stories tended to isolate Edie as the odd one, the one who did not fit, because she claimed ability—the ability to take care of herself, the ability to base her decision on the strength of *her* experiences, and the ability to determine what is right for her. Thus, she can conclude that the stare, including the medicalized gaze, is society mirroring the expectation of inability. This she rejects as applying to her. She demonstrates this rejection by focusing on her experience of ableness and by claiming the responsibility to make choices about which medical options fit her life.

These stories of inner protest demonstrate the importance of a woman knowing herself well so that she can differentiate between society's narrative for her and her own life. This includes having a clear picture of her own abilities and limitations. Recognizing abilities and assessing limitations is a difficult task for many women. Because of the idealized images of women in consumer cultures, a woman is more likely to have intimate knowledge of her "flaws" than her strengths. Though true for nondisabled women, this tendency has at least a double impact on women with dis/abilities. There is a danger for women with dis/abilities to misread the extent of their limitations—either to concentrate primarily on noting the activities they cannot do or minimizing their actual limitations in an attempt to prove themselves competent.

Limitations exist for everybody, *and* limitations have boundaries. Joanne recognized that limitations are related to environment or activity. During my interview

with her, she said, "From a dis/ability point, I'm disabled. But sitting one to one, like

right now, I don't feel disabled talking to you and being with [a friend who was present]."

Edie refuses to accept the limitations others want to attribute to her. Thus, she pushes

herself to see what she can do. By pushing the boundaries of her limits, she expands her

awareness of her abilities. She is empowered by the knowledge and utilization of her

strengths.

A recognition of abilities and an honoring of limitations are both important.

Camille is quite confident about her abilities. "I'm relatively successful as an artist. . . .

I'm really good at what I do, at my art." Increasing limitations become opportunities for

creative approaches. Recently, the spasms and involuntary movements have extended

beyond her neck to her hand and arm. "But I compensate. . . . If I have to write, then I'll

hold my hand steady with my other hand." At times, she has to redo sections of her art

work if her hand jerks while she is working. She speaks about her latest difficulties with

disappointment. Yet, she relays her various solutions in a very matter-of-fact way with

no hint of frustration. Finding new and workable ways to deal with difficulties is all a

part of life. It does not matter if one has a disability or not. Discovering what works is

an achievement. Holding firm to the knowledge of both abilities and limitations supports

the inner protest.

Effective pastoral ministries recognize the value of the inner protest by people

with dis/abilities. Helping nondisabled people value and welcome this protest is a

practice pastoral caregivers and counselors can offer to nondisabled persons and

communities of faith.

These stories of inner protest demonstrate that something in the human spirit, arising, perhaps, from an irresistible affirmation and a sense of one's inherent value, resists being diminished.[3] This aliveness and its resistance to diminishment and annihilation is the source of the inner protest. It leads to action in interpersonal relationships, and it is an action itself—to stir oneself up enough to resist diminishment. It keeps one holding firm to one's own sense of self rather than being unduly swayed by the views of the majority. It keeps one on one's own path rather than on the path culture dictates is appropriate for women with dis/abilities.

Saying "no" to injustice is an important action. Saying "yes" to life—affirming life and promoting justice and well-being for all people—may follow. A challenge to experiences of diminishment and dehumanization is to live abundantly, to be fully the person one is with all the strengths and limitations that may entail. Resistance is an important step between social devaluation and abundant life, especially resistance that is rooted in a sense of aliveness, that expresses a vitality and energy for life, that looks forward to enhancing the well-being of self and others.

Caring for the urge to resist is appropriately a task of ministries of care. Resistance that says "no" to false representations and "yes" to life in all its potential abundance can be cultivated—not forced, but nurtured—in another by a wise person. Such nurture includes creating a space where the innate "no" to diminishment can be expressed, affirming that "no" is a legitimate response to injustice, and weaving together into one's conscious story the times when a "yes" to life for self and others is enacted.

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[3] See Chapter 5 referring to Kathleen Greider's work on aggression and her book *Reckoning with Aggression* (Louisville: Westminster John Knox Press, 1997).

Women's stories about staring and other devaluing encounters reveal not only internal reactions but also a variety of interpersonal responses. Chapter 8 investigates seven interpersonal responses identified in the narratives.

CHAPTER 8

CONFRONTING THE STARE:

RESPONSES TO INTERPERSONAL INTERACTIONS

The stare objectifies, but women with dis/abilities are not merely objects created and surveyed by nondisabled people. Women with dis/abilities are the subjects of their own lives. In the previous chapter, we looked at some internal dynamics sparked within the women I interviewed around encounters with the stare. A response in an interpersonal exchange is often necessary or desired. This chapter examines some of the ways the women I spoke with responded interpersonally following a confrontation with a person who stared at, or focused on, their dis/abilities or who avoided them.

The seven sections of this chapter indicate seven ways the women chose to respond to the stare or other devaluing interpersonal interactions. The responses were: 1) seeking a safe place after a devaluing experience; 2) deciding to "turn the tables" on the person who stares; 3) telling the story from their perspective; 4) speaking up to resist the imposition of another's agenda; 5) following through on their own expectation that they will be treated with the same respect due any human being; 6) educating others by sharing the insights of their own experience; and 7) "turning off" the power of the stare in order to "turn on" the power of their lives.

Two critical goals in caregiving involve working with persons and communities around issues of social exclusion of persons with dis/ability. The first is changing common paradigms about dis/ability—the ways we think about dis/ability. The second involves seeking well-being and the full engagement of life for persons with dis/abilities—how we practice caring when dis/ability is a fact of life. These goals are

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not achieved by one group of people (the nondisabled) doing "good works" for another

group of people (those with dis/abilities)—it must be a joint effort.

Seeking Sanctuary

There are times when retreat is an appropriate response. After Rebecca

encountered the staring man on the street who said, among other things, "it sure is

horrible to have to look at you," Rebecca took the time to deal with what had just been

forced upon her. When she returned home, the emotions that she had held in check came

tumbling out, and she cried. She cried, because "it just finally hit me that that is how

some people see me." She cried, because his statement seemed to her in that moment of

woundedness the reason for all the other stares where no words had been exchanged. She

cried, because internalized ableism rose to the surface and, for a brief period of time, she

believed the dominant cultural views about disability and attributed those to herself. Her

decision to retreat provided a time and space to grieve the thoughtlessness expressed in

the encounter and its many ramifications; and it gave her time to return to her own

perceptions of herself and the world. Then, she could go on with her life.

Joanne deliberately chose to retreat from confrontation with her family, remain

silent about her hurt, and hope for change. This decision followed a painful incident that

caused a change in her relationship with her family. It involved the reaction to Joanne's

dis/ability by friends of her teenage niece.[1] The event occurred on the occasion of a

family celebration. The party had already begun by the time Joanne arrived.

> I guess the most painful one [staring encounter] would be with my family. Just an
> incident that happened with my niece. (She points to the niece's picture on the
> mantel.) . . . They had a birthday party with my other niece and my nephew at the

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[1] This was more an encounter with a disdainful glance than a stare. But, as Joanne recalled this
event when I asked about staring episodes, she places it in the same category as encounters with a stare.
The encounter was a devaluing experience to her, the result of being observed and judged negatively.

skating rink with all their classmates. And I was in my chair. And, when I came in, naturally I went to my family and kids and I went, "Hi you guys!" They came and gave me a hug and everything. And then I kind of stepped back. Some of Tamara's [a pseudonym] girlfriends said to her, [quoted with disdain in her voice] "Who is that crippled girl?" And so Tamara goes, [spoken with disinterest] "I don't know; come on." So ever since then, Tamara doesn't want to be with me out in public, and so, and that's the most painful thing. 'Cause when they have barbecues, and things like that, and this week-end she's in a musical, and she doesn't want me to come. She doesn't want people to see me, you know. So, that's the most painful thing.

Joanne is extremely hurt by her niece's disavowal and being left out of the events in her niece's life. This exclusion has expanded to any gathering where people who are not family members will be present. Joanne hopes that Tamara "will outgrow it," and they can go back to enjoying each other's company.

Her family's embarrassment about Joanne's dis/ability has a long and painful history. She has decided not to say anything to them about their actions. She does it to stay connected with them. She takes this path of great pain, because the path of confronting family members, she believes, is fraught with even greater pain and disconnection. Joanne's therapist challenges her decision to remain silent and encourages her to confront members of her family. In certain situations, that could be a positive course of action and lead to better relationships. But Joanne is convinced that her family's response would be to distance themselves from her even further, and to refrain from telling her any news about the activities of family members in addition to excluding her from events. She enjoys family gatherings when she is present and does not want to jeopardize those. Therefore, she chooses to say nothing and accept what they are able to offer.

Rebecca's and Joanne's decisions in the incidents described above involve retreat to a place of safety. The words *sanctuary* and *retreat* have religious connotations.

Christians call the central place of corporate worship a sanctuary—it is sacred space. The word is also used to designate a place where persons in danger may find safe refuge. Sanctuary as place is temporary. People come for a short time and, then, return to the world renewed or restored. Retreat is temporary as well—a time set apart from daily activities to intentionally be open to the presence of the Holy One—to pray, to reflect, to search one's heart, and sometimes to open oneself up to a "next step" in life's journey. When one is confronted with a devaluing experience, such as the stare symbolizes, one may decide on withdrawal and shelter, settling into a safe place for a period of time while trying to handle the stirred emotions within or because the other options are not satisfactory.

A retreat is taken alone, though a companion may be available for short periods of time to guide the seeker's deliberations. Persons in ministries of care and communities of faith may be able to offer sanctuary, safe places and companionship, for women with dis/abilities who have had painful experiences of the stare or other incidents of devaluation. Pastoral caregivers and counselors can facilitate retreat-like activities. For example, it can be healing to recall places, persons, or activities that have been restorative in the past and may be so again. Going on retreat through caregiving may be a time to reflect on and make choices about the new narrative one is writing in one's life. Also, companioning women with dis/abilities through healing from hostile encounters requires communities of faith and persons in ministries of care to face and challenge the dominant ableist narratives they have come to believe, often unconsciously.

Turning the Tables

Turning the tables takes the form of returning to the speaker the words, or the doer the actions, just received by a woman with a dis/ability. Responding with a quick "come-back" following another's inappropriate word or deed that highlights her dis/ability is a tactic Camille wishes she could carry out more often. At times, she strategizes clever remarks she hopes to use in future situations. She does not generally use them, both because the episodes happen so quickly that she is momentarily stunned and speechless, but also because it is not her preferred way of being in the world. There are times, though, when she would like to respond in kind after something thoughtless is said to her. If someone is judgmental toward her, a part of her wants to be judgmental back. When an individual is "nasty and derogatory" to her, she fantasizes firing a quick and cutting comment back to them. Rebecca, Edie, and Liz also expressed a desire to be able, at times, to trade insult for insult. In actuality, it is rarely what they do, though they are capable of being quite blunt and clear.

In the following narrative, Camille recalled a time when she spoke up to a man she noticed staring and pointing at her. He initiated the conversation by offering her a piece of cloth in order to hide what he called her "problem," that is, her dis/ability. Camille, who complains that she cannot think fast enough to come up with clever repartees in the moment, turned the tables and suggested that the problem does not rest with her, but rather with him.

> I was at party with a boyfriend and a friend. There was a very drunk man and
> from a distance he was following me ... I could see him pulling people aside,
> leaning and saying something to them, and pointing at me. I told my friends and
> they didn't believe me—until he came up to me, handed me a scarf, and said I
> might want to "cover up that problem" of mine. I looked him straight in the eye
> and said, "No, *you're* the one with the problem" rather loudly, I think. And he

kept saying, "Don't you want to cover that up?" I said to my boyfriend, "Let's get out of here." But not before [my boyfriend] picked me up, hugged me and swung me around, and told me how proud he was of me for standing up to that jerk—and apologiz[ed] for not believing me. I tell you, it really helps to have support, even if it's a little late.

Camille rejected the idea that her dis/ability is a "problem" she needs to hide. She boldly proclaimed that the man who made such a suggestion was the one with the problem. The man did not comprehend what she was telling him. He continued to press his point. Thus, Camille's turning the tables seems to have its own satisfaction and does not depend upon others changing their minds or coming to a new awareness of the nature of dis/ability. Camille chose to leave the party rather than stay, but it was not an act of withdrawal and silence. She had said what she needed to say. Not everyone receives encouragement from others in their efforts to resist ableist comments, but Camille did on this occasion. Her boyfriend, who until the man approached Camille directly had dismissed her concerns that someone was staring at her, reversed his position and applauded her for speaking up to this man. Her appreciation of his actions reveals how support for challenges to cultural stereotypes and values can be an act of care.

Similar to the incident of Camille's, Liz reported a time when someone said to her, "What's wrong with you?" Liz immediately replied, "There's nothing wrong with me, what's wrong with you?" As she reflected on that exchange, which took place when she was an adolescent, she said, "Yeah, I move differently, [but] . . . in the greater scheme of things, that is not much." She rejected the idea that dis/ability naturally leads to a negative valuation. Her quick and firm response that there was nothing "wrong" with her was made possible by her self-valuation. "Deep down inside I knew there was nothing [wrong with me]."

Turning the tables can take a nonverbal form. Liz recalled a time when she was in her twenties and on a tour in Europe with other people with dis/abilities. The people on the tour were boarding a bus when Liz noticed a man on the street staring at them. She became angry. "We have every right to be here doing our thing. . . . He was looking at us like we were freaks. We are not freaks. We are out here doing what we want to do, all of us having a good time on this trip. . . . How dare he!" Liz thought his actions were wrong and dehumanizing toward all of them. She began to stare back at him and point and laugh. She continued to stare until he became aware of her behavior toward him. Then, he left.

Turning the tables can have a retaliatory and defensive edge. Retaliation is not generally the best use of one's energy. It is not an effective means of individual and social change. Nonetheless, defending one's boundaries when they have been trespassed is not inappropriate. Having misrepresentations directed toward one can be a form of trespassing boundaries. Intrusions of psychic space by making and acting upon assumptions of a person having something "wrong" with them, or naming a dis/ability a "problem," or staring unashamedly at a group of persons with dis/abilities invites correction. As reported in chapter 4, Adrienne Asch tells of a incident when a stranger sat down near her while waiting for a speaker to begin a presentation and told Asch, who happens to be blind, to let the woman know if she needs anything. Asch responded that the woman could let her know if she needed anything as well. As a part of keeping boundaries, turning the tables seems to be an attempt to move an encounter from an inappropriate superior-subordinate or helper-needy interaction to a level one.

Turning the tables as a defense of boundaries, a proclamation of self-value, and a means of leveling an interpersonal interaction points to conflicted relationships between nondisabled people and persons with dis/abilities. Caring for relationships is an aspect of ministries of care. Relationships between nondisabled people and people with dis/abilities can be badly skewed, with the nondisabled person assuming a leading role, whether that be one of "helping," or naming a personal trait as "wrong" or a "problem." One element of effective care involves acknowledging the particular challenges of being a woman with a dis/ability and celebrating with women when they respect and value themselves enough to put limits on how far society, in its narrow focus, can tread on their dignity. Care can also be offered to the person wanting to "help" when the other is not of the opinion that she needs such "help."

Telling the Story

In making a decision about how and when to respond, a woman's decision to turn the tables may result in challenging misperceptions by others. It is also possible that persons at the receiving end might be confused or startled at the response, not understanding that they have been introduced to another paradigm. Communicating an alternative perspective can take place by a woman simply telling her story from her own point of view. For example, though Joanne is inclined to avoid confrontation with her family, she does not always take that path under other circumstances. Joanne provides spiritual leadership for a women's group in her denomination. She is, therefore, occasionally invited to take a leadership role at week-end spiritual retreats.

On one retreat, she was one of two persons assigned to a particular table as table leaders during mealtime. When she initiated conversation during meals, she noticed the

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others at the table would respond not to her but to the other table leader. As the retreat was ending and all were gathered for processing the experience, Joanne expressed feelings of exclusion and insignificance—she bluntly told the group that their actions conveyed their perceptions that her presence was unnecessary. She described the difficulties of trying to engage in conversation with persons who ignored her. It was a moment of awakening for several of the participants. In Joanne's story, one woman recognized her own behavior toward her elderly mother and vowed to change that pattern of interaction.

Ministries of care can play a role in mending hurt relationships, in reconciling persons in a community where divisions exist. Joanne had a difficult week-end and was hurt by the exclusion. The women at the table with her may have been experiencing discomfort or annoyance, which they tried to alleviate by ignoring her. When exclusion and distress enter an intimate gathering, such as a retreat, the whole community suffers. Reconciliation is not furthered by avoiding a painful situation. Avoidance maintains the distance between persons.

By telling her story, Joanne took the first step toward reconciliation. A frank exchange of feelings, thoughts, and experiences can open up a dialogue between people with dis/abilities and nondisabled persons that rarely takes place—what it is like to be a person with a dis/ability facing exclusion and what it is like being in the presence of a person with a dis/ability when feelings of discomfort or annoyance arise. The reconciliation is not only a matter of including Joanne, nor of lessening the anxiety of the other women gathered, nor even being able to dialogue about an issue that raises many feelings. Rather, it enables each person to become more fully human, increase the

capacity for crossing the dividing walls of relationships, and become more Christ-like, all reasons a person might engage in spiritual examination of a retreat in the first place.

Speaking Up

Speaking up openly challenges distorted perceptions that are revealed in gestures, behaviors, and speech. Edie understands the stare as a reflection of society's expectations of inability in the lives and actions of women with dis/abilities. She associates the medical profession's ever-present, constantly evaluating surveillance with the stare. A recent hospitalization was on her mind when we met, and Edie focused on interactions with the medical community and their communication of an assumption of inability to her. In chapter 7, I examined some ways Edie's experience of herself and her needs conflicted with the medical community's perception of her. I also looked at the internal protest that arose within her to allow and even encourage her to hold fast to her own reality. Now I want to continue that thread to highlight the contest that ensued between Edie and the medical experts.

Edie was hospitalized to treat a decubitus ulcer, a skin sore that, if left unchecked, can go deep into the body. Decubitus ulcers form at pressure points when one stays in the same place for too long, such as when sitting in a wheelchair without frequently repositioning oneself. People with spinal cord injuries have the disadvantage of not being able to feel the pain from the sore. Therefore, a skin infection can go unnoticed for a long time. This is the situation Edie found herself in and the reason for the lengthy hospitalization. As she was preparing to return home, her medical advisors recommended home nursing assistance and special equipment. As she tells it, they said she needed a hospital bed, a rolling cart that would keep her off her back, a special

cushion for her chair, and someone to assist her—at the least, a nurse to come check the wound twice a day.

But Edie will not hear of it—she speaks out. She is convinced that the special equipment would be a burden rather than a help and that assistance in caring for herself is not needed. She speaks out—with great intensity—to protest their plan for her. "No, I don't need that. That's not necessary. No, I don't need a hospital bed. No, I don't need this crazy huge heavy wheelchair cushion. I understand why you want me to [have these things but] I don't need it!" She reports that "they were very, very resistant to [her refusals]." They continued to urge her to follow their instructions regarding equipment and personal assistance. She eventually relented somewhat and allowed a nurse to come twice a week. "That was good, I actually did need that and learned to see that."

The medical community likely saw her as an uncooperative patient going against the very best medical advice. But that would be too simple an explanation. Edie has her reasons for speaking up and rejecting their advice. In her view, following their recommendations would have created more problems for her than they solved. Their suggestions had merits from a physiological standpoint, but the life she had crafted for herself after the accident would have been compromised by extra equipment and personal assistants. Implementing their recommendations, she believed, would have decreased her abilities rather than increased them: first, by encouraging her to rely on people and equipment and, therefore, not use her own body to do the things she is used to doing, and second, by lessening her confidence in herself and her own hard-won recognition of her abilities.

Her response was based on previous experience. When she came home from the rehabilitation center following her accident, she had with her a carload of equipment, which she eventually learned was unnecessary. In fact, the equipment became an encumbrance if she wanted to go on vacation. It was at such a time, when the equipment was not available, that she learned that there was a lot she could do that no one had told her about. She began to question the assumption she was unable to do particular activities. She would test out a movement, attempt new things, and discover her abilities and limitations for herself. Now, she was at another fork in the road, and people were pushing equipment and assistance on her.

This time she was not automatically willing to take their suggestions. She decided that her own knowledge of her body and her circumstances as defined by the life she was accustomed to leading would be the determining factor of what to agree to or refuse. Thus, as she was not willing to build special equipment and assistance into her life, she decided to speak up and say "No." She had to "fight and argue," as well as trust herself to hold on to the truth of her ableness when others mirrored need and inability.

Resistance to inaccurate cultural messages can take the form of persistence in the face of opposition, including opposition from caregivers. Edie's decisions were not refusals in order to be difficult. She carefully evaluated the medical opinions but also took into account her own expertise and knowledge of the way she lives her life, and she wanted to continue to live her life according to values chosen for and by herself.

Persons in ministries of care can be a sounding board for women with dis/abilities in sorting through their priorities, assessing their capabilities, and making plans to speak up to inform others of their priorities and capabilities. Chaplains may be able to

intervene on behalf of a woman who is being unduly pressured to accept unwanted assistance or treatment. Some persons who have been patients off and on for a long period of time become used to ceding their care and life choices to the medical professionals. Furthermore, it is easy for caregivers (medical, personal, and religious) to fall into the pattern of treating as children the people to whom they provide care, assuming they know what is best for people with dis/abilities. Of course, adults have the responsibility—and should have the right—to make decisions for themselves. Caregivers who are aware of the danger of infantilization can encourage and support women in taking a central role in making decisions about their own care and treatment.

Expecting Respect

People with dis/abilities can become invisible to others. The parental command to not stare at people with dis/abilities turns into not noticing, pretending the person using the wheelchair does not exist, or assuming that a person with a dis/ability is not waiting to do the same thing that the nondisabled person is waiting to do. Liz tells of waiting to check out at a hotel or in a grocery store only to have someone step in front of her as if she were not there. She has been rolling down the sidewalk, approached by a crowd of people walking toward her, and has moved out of their way without any acknowledgement on their part that she was present. She has come across people standing in the middle of a curb cut, carrying on a conversation and oblivious to the fact that they were blocking her path.

Over time, Liz has decided to set limits on her accommodation and politeness by stating her needs in the face of apparent discrimination and invisibility and by expecting that the respect extended to others will be extended to her as well. When someone begins

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to cut in front of her while waiting in line, she will say, "This is my turn" or "I had this place in line." When others are coming toward her on the sidewalk, she no longer yields the way but takes the attitude that there is room for all. When the curb cut is blocked with folks chatting, she will say, "Excuse me, you're standing in the middle of the curb cut." She has learned that expressing her own expectation that her person and endeavors will be respected is necessary in order for her to get her needs met.

Some of what Liz encounters in situations where she feels invisible has to do with social expectations. Modern society assumes that people will be an average height and move in a certain way. Rolling on wheels is not one of the expected ways of moving in the world. Some nondisabled people assume that people with dis/abilities have persons helping them, that women and men with dis/abilities are not the ones grocery shopping and waiting in lines to check out. Alternative narratives include an awareness that people with dis/abilities are in this world doing ordinary things, such as buying groceries, paying for hotel rooms, moving down the sidewalk, and, as Joanne's narrative above pointed out, carrying on dinner conversations.

Persons in ministries of care can teach respect for people with dis/abilities by modeling it through their own interactions. Dignity is reciprocal, expected of both people with dis/abilities and nondisabled people toward one another. All people can learn to ask, "Excuse me, are you next in line?" It does require that people be aware of their environment and learn to expect things that we were not taught to expect. Liz does not need others to let her go first. Some people offer that, and it makes her uncomfortable. She is quite willing to take her turn and wants others to do the same. This is giving and receiving respect.

Educating

For some of the women with whom I spoke, one response to the stare is to educate—to offer the one staring the opportunity to learn something new about a woman with a dis/ability. These teaching moments may be verbal or non-verbal; they may involve a demonstration or answering questions. The goal is to communicate something about women with dis/abilities that the observer or questioner does not know or has never been exposed to. It is not necessarily a role they entirely welcome—they fall into it when they encounter unknowing in another person and decide to give that person an opportunity to broaden her perspective.

Though Edie dislikes the message the stare communicates to her (the expectation of inability), she is not put off by being the object of the stare in and of itself. She attributes this to her experience as an exchange student the year before her accident. "I was in a city of two million people and was maybe one of fifteen blonds. Plus I didn't dress the same. . . . I drew a lot of attention that way. I made it kind of fun. It didn't bother me." Neither, she says, does it bother her now when she attracts attention, when people stare at her.

Edie uses the attention to educate. Because she considers the stare to be the result of a lack of knowledge about people with dis/abilities, she likes demonstrating what she can do. When people ask her if she needs help with tasks she is quite able to do, she enjoys their surprise as she politely declines the offer and proceeds to do what others expected she was unable to do. Some people offer to help her put her chair in the car, and she says, "I have seven years of practice—it's okay," or "No, thanks, I don't need it." If they express surprise by saying "Oh, you've got a good system," or "You do that pretty

well," she takes it as a compliment. When she rearranges the furniture in her apartment and friends take notice, she delights in their recognition of her physical abilities. By demonstrating "that I can do something with the rest of my body," she challenges the stereotype of inability, educating all who see her.

Rebecca also finds herself in the role of teacher at times as she responds to questions asked of her. "People ask me 'How [do] you drive?' and the look on their faces is so confused it's as if they were asking me 'How do you fly?' or 'How do you beam yourself to Mars?' It seems so foreign to them. But once I just explain to them 'There's this pedal and I push it with my hand' it's like 'Oh, okay.'" Rebecca is particularly open in responding to children's questions. She believes it is a chance to tell another story of dis/ability that is not always available or recognized. When children, especially young children, notice her, they are not hesitant about asking questions. Rebecca takes full advantage of this brief interaction to challenge prevailing notions about dis/ability.

> There are countless times [when] children will come up and ask me questions. And I *love* answering children's questions. . . . I love it in the sense that I'm glad they're actually asking, and I'm glad I have the opportunity to answer. And, for the most part, particularly really young children, their reactions are so honest and so quick. They don't understand why I don't have legs. I tell them and then they don't care—they really don't care. . . . I love answering children's questions because they just want to know, especially really young children. I don't want to say that they haven't internalized any prejudices yet, but there's certainly not the same value judgment that there is for adults when adults ask questions.

To Rebecca, young children's questions are simply a matter of seeking information about something with which they are unfamiliar. Their curiosity is satisfied with straight-forward answers. Unfortunately, the desired educational outcome—the child being exposed to a counter-cultural paradigm of dis/ability—is sometimes short-

circuited by an adult, thus reinforcing societal values rather than challenging them. But

not always.

> There are so many times when I've been having a conversation with a kid that I
> think was good for both of us—well, I'll come back to what's good for me in a
> moment—but good for the kid because they're getting to ask these questions and
> understand something about difference that they didn't know, that maybe will
> stick with them for a while. And inevitably their mother or their father or some
> adult comes and just drags them away. And they [the adults] say, "Don't talk to
> people like that" or "You're being rude." Very rarely do the adults acknowledge
> my presence. They might look at me and say, "I'm sorry" and then look away
> really quickly. But as often as not, they don't talk to me—they just drag the kids
> away. That kid, then, learns that there's something wrong with me, that there's
> something wrong with talking to me. And I think that's why I say I love talking
> to kids, because I see it as this stolen moment to do something subversive before a
> big person comes along. [I ask her about her choice of the word "subversive."]
> Subversive in the sense that—I hate to quote a bumper sticker—I'm subverting
> this dominant paradigm that you're not supposed to talk to people with
> disabilities, that whatever happened to them, or whatever way they were born, is
> bad. There is something bad about it—it's secret, shameful—that's why you
> can't talk about it. So it's all about our own individual problems that nobody else
> needs to deal with. And so by acting like it's really not a big deal—this is
> something that happened to me, this is just the way I am, the way I walk,
> whatever—it's not shameful anymore.

When Rebecca gets this "stolen moment" to talk to a child who noticed her bodily

configuration and asked a question, she is introducing them to an alternative narrative

about dis/ability. Dis/ability is just something that happens. It is not imbued with

negative value.

Rebecca is clear that these interchanges not only help the children but are

insightful for her as well.

> When I talk to kids . . . it reminds me that people just don't know. The kids'
> questions are so innocent—they may be blunt, and they may sound rude, except
> they're coming from this place of curiosity. So sometimes it helps me, in terms of
> adults, to see those stares as stares of curiosity instead of stares that are value
> judgments.

It helps her reframe the stares she gets, the stares where no questions are asked, no comments made, because it is those stares that are open to a variety of interpretations. It helps her get through her day with ubiquitous stares by considering the possibility, and even choosing to believe the likelihood, that most stares, that stares until proven otherwise, are gestures of curiosity, not value judgments. In this way, Rebecca subverts the dominant paradigm by refusing to believe in it herself, by refusing to believe that it holds much influence in nondisabled people's reactions to her.

To educate another, though consciously chosen, is not necessarily a priority for women with dis/abilities. It is often done because the opportunity presented itself and the other options—to not inform, become annoyed, reject the question or attention—seemed less desirable options. Sometimes women with dis/abilities do not want to answer the questions directed to them. After Rebecca enthusiastically announced that she loved questions from children, she offered the caveat, "Well I don't know if I love it, there are actually times when it's kind of a pain." But then, she proceeded to give reasons why she said she loved it. Liz tries to corral her impatience if a child is asking her a question, because she thinks it is important for them to have a positive experience with a person with a dis/ability.

It is gracious of Edie, Rebecca, and others to volunteer their deeds and words to teach the public about lives with dis/ability. Being scrutinized as they are, their behavior inevitably is an education for those with whom they come in contact. However, it is not enough. Ministries of care can be involved in educating nondisabled people in ways that fit into what they are doing already. For example, a class on parenting could include in the curriculum a session on the diversity that exists in the human race and ways to help

children interact with persons who may look or talk or move different than they do or have different traditions, different ways of approaching the world, and so on. Then, when their children approach someone like Rebecca who is willing to talk with children, the parents are prepared to help the children negotiate a conversation with an adult rather than drag their children away. There is so much variety in humankind and, rather than being frightening, it could be exciting and interesting to be exposed to new perspectives, to broaden parents' and children's horizons.

When working on an individual basis with women with dis/abilities who are subjected to many questions by children or adults, it may be helpful to practice educational responses. This might include ways to engage questions or comments or to disengage from them. It is also important for a person with a dis/ability to respect her own comfort level and find a way to decline, if desired, or to convey only the information she feels able to share. Children with dis/abilities may particularly be in need of ideas about and practice in responding to questions from other children and adults in a manner that feels comfortable to them.

Turning Off the Power of the Stare and Turing On the Power of Life

Turning off the power of the stare to devalue and humiliate enables a woman with a dis/ability to turn on the power to live her own life. The ultimate form of resistance involves living one's own life and not the life society has scripted for that person to lead. Writing an alternative narrative with one's life subverts and confounds dominant societal assumptions.

One response to staring encounters takes place after the confrontation has occurred. This response was common to all the women I interviewed. Sometimes a

woman refuses to carry the pain and the humiliation of the staring encounter with her and decides to let it go. It is not easy to do, does not happen with each encounter, and is not guaranteed to be permanent. Nonetheless, sometimes a woman is able to put a staring encounter behind her. The encounter is relegated to the past so that she can get back to living in the present. She turns off the power of the stare gets on with the task of writing a life narrative that fits her.

Rebecca demonstrates this kind of response when she describes what happens when she makes the transition from internalized ableism to living her life again.[2] She reports that eventually her tears have dried up and something catches her attention, such as a ringing phone that has to be answered. The devaluing stare loses its power over her, and she gets back to full engagement with life.

Edie has much in life she enjoys, too. Her time and energy go into advancing her hopes and dreams, not focusing on society's stereotypes of women with dis/abilities. As far as being a woman with a dis/ability, "to me it's always just been almost not a thing. I feel that there are other things to do. When I've got to go to the store, I've got to go to the store. It doesn't matter what I look like sitting down at the store." In the beginning, she felt as if she were on the defensive, that she had to prove herself. "Now I don't feel that so much, because I've just dealt with it for so long. Some people are going to think I'm stupid; some people are going to think less of me as a person, or they're not going to think of me as a person, whatever. But it doesn't really matter to me anymore." There is the business of living to get on with.

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[2] See Chapter 7.

Ultimately, Edie wants to become involved in a project dealing with the care and preservation of wild animals. Meanwhile, she has quit graduate school in order to do "something smaller." In high school, she worked as a cashier in a grocery store. She enjoyed that and would like to try it again. "It doesn't seem like much, but it's really a big responsibility." She makes it a priority to be nice to people even, or especially, in brief interactions. To give people special attention that might bring "unexpected happiness" is important for her.

Her Buddhist beliefs guide the way she orders her life. She places special emphasis on understanding the other person's perspective or situation and showing compassion and kindness to that person even when she might not feel like it. Edie is also fond of stretching her mind and has identified a game show on which she would like to appear as a contestant. Preparing for an audition occupies her time. Like most persons, she is busy and generally content.

For Camille, beginning a business brought her into public view in a way she had not experienced before. She believes that both personal and business relationships have been affected by her noticeable dis/ability, and she acknowledges being self-conscious about her neck spasms and head movements. Yet, it does not stop her—she continues to do those activities that need doing or that she enjoys. Whether the public responses to her are stares or avoidance of contact, both of which she reported, she struggles through them and goes on with her life. She turns off the power of surveillance and gets on with her life.

The lives that women with dis/abilities lead are not compatible with the dominant narratives about dis/ability. The dominant paradigm needs to be resisted and altered or,

as the bumper sticker to which Rebecca referred states, subverted. Feminist

psychotherapist Laura S. Brown engages in what she terms a "practice of subversion" in

her work with and for survivors of trauma.[3] Though a secular therapist, her Jewish

religious training as a child informs, even grounds, her work in challenging dominant and

oppressive patriarchal narratives. Brown tells the story of her Bat Mitzvah. At the time

of her ceremony, females were not allowed to read the Torah, the first five books of the

Bible, and a passage from the Haftorah, writings by the prophets, was substituted.

Reading the Haftorah as a substitute for the Torah, Brown explains, has roots in a time

long past.

In the second century BCE, the Israelites were forbidden from reading the Torah

by an oppressive regime that occupied their land. So they did not read the Torah; they

read a passage from the Haftorah that conveyed the same message. The people,

therefore, both followed the edict and subverted it at the same time. Regarding her

experience of emulating the practice of the faithful in ancient Israel, Brown writes: "I am

proud to have been the recipient of this tradition of resistance to oppression and to have

learned at an early age that the reading of the Haftorah symbolized my participation in a

heritage of unwillingness to accept an unjust status quo."[4] Ministries of care can be

practices of subversion when they participate in turning off the power of the dominant

narratives about dis/ability by refusing to have those narratives inform their interactions

with and about people with dis/abilities.

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[3] Laura S. Brown, "The Private Practice of Subversion: Psychology as Tikkun Olam," *American Psycologist* 52, no. 4, (April 1997): 449-62.
   [4] Brown, 451.

The text selected for Brown to read at her Bat Mitzvah was from Ezekiel 37—the

story of the dry bones. Reading this text now reminds her of trauma survivors and their

process of recovery, who experience, as Ezekiel did, a loss of soul ("stony heart"), among

other things.[5]

> [I]n Jewish ethical thought . . . the most basic strategy for saving and healing the
> world [is] the act of saving another human life. . . . And by saving a life I mean
> not simply keeping the body breathing but taking the dry bones out of the valley
> and putting sinews and flesh onto them—in the terms of psychotherapy not
> merely symptomatic reduction but *the empowerment of people to full aliveness, to*
> *a voice of their own, and to a sense of peace and a new heart, energizing people*
> *to redeem themselves from exile.*[6]

Resistance to practices that annihilate can give rise to the power of aliveness,

voices that tell their own stories, a new way to be in the world, and the energy to redeem

oneself and others from exclusion and diminishment. Brown describes her work as a

"conscious act of social justice making," an act of "tikkun olam, the healing of the world,

through the healing of the one human life" who is present.[7] Ministries of care when

engaged in seeking justice and well-being for people with dis/abilities share goals with

Brown's practice of subversion.

Ministries of care can be practices of subversion by joining women with

dis/abilities in challenging the authenticity of the dominant cultural narratives. In an

environment (social, physical, and religious) that is not created with dis/ability in mind,

people with dis/abilities refusing to exclude themselves is subversive. In a culture where

the typical pattern is that someone else, generally from a "helping" profession, knows

what is best for people with dis/abilities, a woman with a dis/ability making choices for

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[5] Brown, 451.
[6] Brown, 453 [emphasis added].
[7] Brown, 452.

her own well-being—whether to retreat and seek a safe place, or respond by turning the tables, or to decide the medical protocol that best suits her life—is subversive. In a society where nondisabled people presume that bodies with dis/abilities can be inquired about or commented on with impunity, a woman with a dis/ability who defends her personal boundaries and expects to be treated with respect is subversive. In a culture where the dominant narratives are believed to be true, people with dis/abilities writing alternative narratives with their lives, and telling their stories or demonstrating their abilities, is subversive. When a common belief about dis/ability is that death is preferable, women with dis/abilities living full lives is subversive. Pastoral practice, whether in a public arena or individual care or counseling, that makes the experiences and insights of women with dis/abilities criteria for assessing embodiment narratives and practices joins people with dis/abilities in offering an alternative narrative about life and dis/ability.

This chapter focused on the ways women with dis/abilities respond to staring encounters and other devaluing experiences. It is the last in a series of chapters that has taken up the matter of the stare from several different perspectives. The following chapter reviews the main ideas presented in this dissertation as well as indicates possibilities for further research.

CHAPTER 9

THE MEANING OF THE STARE REVISITED

The manner in which one person looks at another conveys an array of messages.

The stare is one way of looking at another, and it is filled with social meaning and cues.

This dissertation centered on the stare as a devaluing symbol aimed at women with

noticeable physical dis/abilities. In dis/ability studies literature, the stare targeted at

people with dis/abilities is a gesture that focuses on a specific physical feature. It is also

a symbol that (re)constructs categories of people with a hierarchy of values, reveals

power differentials, communicates social devaluation, and creates attitudinal barriers. It

is life-restricting rather than life-enhancing. The devaluing stare signifies an obstacle to

well-being for women with dis/abilities and perpetuates an unjust social climate based on

appearance.

Summary

In the previous chapters, I analyzed the stare as a cultural practice and a means of

communication, and examined the effects this practice has on those who are the object of

the stare. As a work in pastoral theology, my method involved the critical engagement of

women's experience of dis/ability with aspects of church and society related to

dis/ability, women, and body for the purpose of seeking transformative theologies and

practices that promote justice for and the well-being of women with dis/abilities and the

communities of faith to which they belong.

The context of lived experience grounds ministries of care in conversation with

theological reflection and the insights from the social sciences. Therefore, throughout

this work, I utilize the stories of women with visible dis/abilities to demonstrate both the

impact of the devaluing stare and resistance to its message. Five women graciously

shared with me a part of their personal experience of living with dis/abilities and being

one at whom others stared, and I relate their stories in chapter 3. Though the stare is, at

times, a painful part of their experience, their lives have many more facets than the

limited ones the stare sees. Their lives write alternative narratives at odds with the

dominant narrative of life with a dis/ability as portrayed by popular culture in the United

States. The narratives of women with dis/abilities are the focal point of this work. These

narratives call into question the adequacy of cultural concepts of embodiment and the

impact of those on culturally-sanctioned narratives of dis/ability and pastoral practice.

Chapters 4-8 consider staring encounters in the lives of women with dis/abilities

from different angles, retaining in some way the questions about embodiment, cultural

narratives of dis/ability, and pastoral practice. I begin with cultural factors and

consequences, move to cultural influences on interpersonal interactions, and end with the

intrapsychic dynamics within and interpersonal responses by women with dis/abilities

when confronting stares.

A primary factor in representations of woman and dis/ability is the high value

popular and consumer cultures place on physical appearance and ability. Human bodies

are evaluated according to the statistical average of various physical characteristics.

Average and above average are considered "normal" and below average is designated

"abnormal." "Normal-average" is expected; "normal-above average" is desired;

"abnormal" is mourned. The assignment of dis/ability puts an individual into the latter

category. Persons considered outside the normal range or below average are stigmatized

and ostracized. This tyranny of the normal by visual assessment is related to the stare and the "oppressive gaze."

The stare, as it affects women with visible dis/abilities, embodies three forms of the "oppressive gaze"—those focusing on dis/ability, on the human as medical specimen, and on women. The stare that centers on dis/ability is intensified by the medicalized gaze and complicated by the gaze toward women. The oppressive gaze visually collects data and files the information in pre-determined categories. It suffers from restricted vision, because it fails to imagine a reality outside of what is already assumed. Persons viewed as categories are neither fully seen, nor known, nor appreciated in all their human complexity. Disregarding the multi-faceted nature of the human being is problematic for ministries of care. The disciplines of pastoral theology, care, and counseling are concerned about the well-being of the whole person, not the individual as a part or as a category.

Christian religious traditions have influenced cultural ideologies that place a negative value on certain bodies, including the bodies of women with dis/abilities. When Christians find dominant values incompatible with experience and with other aspects of heritage, we are obliged to find alternative narratives within Christian traditions to reform concepts and practices that cease to be life-giving. Rather than denouncing the worth of bodies in general or bodies with dis/abilities in particular, we can claim the goodness of all bodies. The presence of unpredictable or deteriorating bodies or bodies with limits neither denies nor cancels the goodness of bodies. Furthermore, the goodness of bodies does not eliminate pain and difficulties. A multitude of features exist in each body.

Communities of faith where all people belong are grounded in valuing the worth and cherishing the complexity of everyone.

Religious and secular representations of woman and dis/ability have not affirmed the goodness of all bodies. Due to the high value placed on physical attractiveness, women are encouraged to correct outward, physical "imperfections" in order to rid themselves of "defects." Throughout the centuries, women have been portrayed as essentially and morally flawed, chiefly because they are not men. People with dis/abilities have also been portrayed as defective and, therefore, morally flawed, because bodies with dis/abilities may not look like or behave like nondisabled bodies. Women with dis/abilities get a double dose of culturally conceived defectiveness. Change comes by challenging restricted, one-dimensional images, by enlarging our views of the multiple dimensions of bodies, and by replacing outdated and unjust theologies and practices with more life-giving ones.

Representations of woman and dis/ability do not adequately reflect the complexity of the lives of women with dis/abilities. Nonetheless, the stereotypes have an impact on their lives. A consequence of bearing culturally-designated difference in one's body is the threat of annihilations, the threat of being reduced to nothing in at least three ways—physical annihilation, annihilation as people of value, and annihilation of gender. Annihilation is not the only part of the story, though, for women resist forces that threaten nothingness.

Women and men with dis/abilities face the threat of literal, physical annihilation. One common social assumption is that death is preferable to dis/ability, that a life with dis/ability is not worth living. The stare participates in this by (re)creating categories of

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superior and inferior and assigning dis/ability to the latter. Not surprisingly, the views of women with dis/abilities about their lives are not so dire. As with most people, women with dis/abilities generally display a desire for life, the inclination to move toward that which is life-giving, and resistance to destructive practices by self and others. Scripture and religious practice, though not unambiguous about dis/ability, contain narratives that proclaim the value of all lives, with or without dis/ability. Pastoral theologians, caregivers, and counselors can join the resistance to discrimination by promoting life-giving practices and by helping communities of faith become places where all people belong.

Women and men with visible dis/abilities face annihilations as people of value. The stare is a symbol of this devaluation. This may result in mistreatment and unnecessary medical treatment. Women with dis/abilities report incidents during everyday life when they are ignored, patronized, and abused. Medical treatment, though at times a blessing, can also become an effort to make the body appear more "normal," while actually decreasing the body's ability to perform particular tasks. Women with dis/abilities resist dehumanization by claiming an inherent worth. Such a claim challenges traditional Christian doctrine that has associated dis/ability with sinfulness.

Women with dis/abilities also face annihilation as women. The stare contributes to the annihilation of gender by seeing only dis/ability. Women with visible dis/abilities are excluded from common, though contested, expectations about nondisabled women—to marry, have children, and work outside the home. Some women with dis/abilities take on these roles and perform them effectively. Women with dis/abilities also contribute to the wellbeing of their communities, families, or congregations in other

ways. Persons in ministries of care have the opportunity to reach across traditional cultural barriers and participate in the restoration of healing relationships between people with dis/abilities, church, and other aspects of society.

Early in life we human beings learn about ourselves through interactions with parents or primary child care providers. The psychoanalytic concept of mirroring seeks to explain the psychically valuable process of seeing a mostly accurate picture of ourselves reflected in the eyes, faces, gestures of, and handling by the most significant others in our first months and years of life. However, if the parent reflects a distorted portrait of the child, mirroring has failed. Encounters with the stare are experiences of failed mirroring, because the devaluing stare reflects the distorted cultural messages of dis/ability, rather than a relatively accurate picture of the person herself.

To explain the mirroring process in the stare, I examined a particular staring encounter in depth. In this one example, we notice the strategies a woman might use to protect herself from damage by a staring encounter, the way the stare and accompanying comments can mirror an image at odds with the reality of a particular person, the power differentials and social status revealed in a staring encounter, and the damage that can be caused by a single staring incident.

Failed mirroring can have a negative impact on a person's image of and relationship to the Divine. Some of the literature in dis/ability studies is particularly and sweepingly condemning of the image of God relative to dis/ability in Christian and Jewish religious traditions. Elements of doctrine and practice have had harmful effects on people with dis/abilities. The narratives of some of the women I interviewed show contact with aspects of Christian doctrine and practice that were off-putting to them as

women with dis/abilities. However, there are alternative traditions, practices, and visions that portray God as embracing all people, including those with dis/abilities. Some of the women I interviewed picture God as One who sees and appreciates the humanness and fullness of a life lived with dis/ability.

Many women with dis/abilities count among their family and/or friends persons who reflect not cultural assumptions, but the fullness of their being, ameliorating some devaluing encounters. People who have received adequate mirroring from others are able to give it in return. Each is blessed by a relationship with the other.

When a person becomes aware that she is the object of a stare that conjures up inaccurate representations, she may note the stirring of internal reactions. The staring episodes that the women I interviewed shared with me revealed at least three internal reactions—clashing realities, internalized ableism, and inner protest. Clashing realities involves a realization of the vast difference in perception between the person who stares and the person who is the object of the stare. This conflict of perspectives can happen anywhere—on the street, in a bus, at the doctor's office, in the midst of an art fair. Women report the clash to be painful, frustrating, confusing, irritating, and infuriating. Clashing realities can lead a woman into self-doubt. Alternatvely, she can become inspired to stand firm in her own convictions of her sense of herself. Ministries of care may be useful in helping a woman to differentiate between the cultural narrative of dis/ability and the narrative of her own life, heal the wounds of discrimination, and evaluate the relative influence of painful versus sustaining interactions in one's life and story.

The second reaction, internalized ableism, occurs when a woman sees herself through the eyes of the one who stares. She judges herself according to cultural values and finds herself wanting. Separating ableist feelings and thoughts from actions allows an individual to experience the internalized judgment but make a decision to act in a way that challenges negative social views of dis/ability. Distancing popular culture's narrative of dis/ability from the narrative of one's life is a step toward diminishing the power of internal ableist thoughts and feelings. Pastoral care and counseling professionals may be helpful by becoming partners for a woman as she "writes her life" allowing internalized ableism a smaller and smaller role in thoughts, feelings, and actions.

The third internal dynamic is inner protest rising to consciousness and voice, challenging diminishment by self and others. Societal depictions generally exaggerate the impact of dis/ability and broaden the spectrum of limitations. Such an approach misses or minimizes other personal features and fails to recognize the wholeness of a person by focusing on a part. Inner protest is aided by knowing oneself well. With attention so often concentrated on what a woman with a dis/ability cannot do, limits can seem to outweigh abilities. Recognizing and honoring limits, while testing and using strengths, give a woman's inner protest the evidence with which to follow through with resistance to unjust structures and situations. Ministries of care have an opportunity to join this resistance—to nourish the urge to resist and to support the communication of alternative narratives for the purpose of seeking and nurturing life-giving traditions and practices for individuals and communities.

In addition to internal reactions, encounters with the stare call forth interpersonal responses by persons with dis/abilities. Seven avenues of response emerged from the women's narratives. First, a woman may seek sanctuary. Sometimes the best action is disengaging from an uncomfortable situation and finding a safe place to recover from a painful situation. Second, women report turning the tables on persons who said or did something that indicated a lack of knowledge about dis/ability. In other words, they respond in kind to inappropriate words or actions. Third, women with dis/abilities, in response to experiences of being discounted and dismissed, tell what it is like to those who are responsible for the damaging behavior. Telling one's story does not guarantee that the listeners will understand and change their behavior, but failing to tell one's story insures that others will have less opportunity to understand and change.

Fourth, women respond to devaluing encounters by speaking up in order to challenge inaccurate perceptions about themselves and dis/ability. This can happen even with the medical community. One woman was persistent in her efforts to declare her abilities to medical personnel, because she felt they had emphasized her limits to the detriment of her capacities. Fifth, women with dis/abilities insist on others respecting their needs and rights. The invisibility of people with dis/abilities can mean that a woman may be ignored while waiting in line or trying to get past others on a sidewalk. Some women decide that being patient while others step in line in front of them or patiently waiting for the sidewalk to clear is too much accommodation. They state their needs and take their turn, insisting that common courtesy be extended to them. Sixth, educating is an activity in which several women take an active part. Their goal is to teach, through words or actions, something about dis/ability or difference that persons

staring at or observing them do not know. Seventh, women with dis/abilities respond to

the stare by turning off the power it has to shame and humiliate and turning on the power

of their own lives and narratives. They leave devaluing encounters behind, refusing to

follow the script society has written about lives with dis/abilities.

One of the women described speaking about dis/ability and her life from her

perspective rather than from the dominant narratives as "subverting the dominant

paradigm." Ministries of care that are concerned with just relationships for and the well-

being of women and men with dis/abilities can join in a "practice of subversion."[*] The

role of ministries of care in the practice of subversion with, by, and on behalf of women

and men with dis/abilities may include rethinking and helping others to reevaluate

attitudes about and assumptions of dis/ability, companioning women with dis/abilities

through the minefields of misperception and painful interactions, and reconciling

communities of faith when negative attitudes and hurtful encounters cause exclusion or

division.

Contributions

This study offers at least three specific contributions. First, it is a pastoral

theological analysis of the stare and lives of women with dis/abilities utilizing the social

political model of dis/ability. The social political approach is used widely in dis/ability

studies literature and dis/ability activism and advocacy. Scholars of religion are

beginning to utilize the social political model in biblical studies, theology, preaching, and

worship, but this has been less true in pastoral care and counseling. Communities of

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[*] A term psychologist Laura S. Brown applies to her work with survivors of trauma. See Laura S. Brown, "The Private Practice of Subversion: Psychology as Tikkun Olam," *American Psycologist* 52, no. 4 (April 1997): 449-62.

faith, as well, have been slow to incorporate this model into their thinking about dis/ability. The social political model is helpful to communities of faith, because it moves the problem of the exclusion of people with dis/abilities from the body with a dis/ability to the communal body. Therefore, the solution to full inclusivity no longer calls for an unattainable change in the body of individual but a restructuring of communities and their practices. It opens up possibilities not available when thinking only at the personal and interpersonal levels.

Second, because this dissertation focuses on the experience of dis/ability from the perspective of women with dis/abilities, it challenges views on dis/ability based on modern empirical cultural norms and theories supplied by nondisabled persons and offers a liberative pastoral theological paradigm. Communities of faith and ministries of care are less oppressive when informed by a recognition and separation of dominant and alternative narratives about dis/ability. Persons are encouraged to get to know each other in all their complexity rather than by cultural representations. Alternative narratives call nondisabled persons to confront and question their biases about people with dis/abilities (and people with dis/abilities to do the same about others with dis/abilities) and construct just and liberating relationships and structures in and through religious community.

Third, this study utilizes the insights of women with dis/abilities to encourage a revisiting and revisioning of theology, psychology, culture, and practice—and the interplay among those—relevant to dis/ability. I examined avenues of alternative thinking about theory and practice with the aim that they will stimulate more ideas about the interactive relationship between theory and practice and result in transformative and liberating pastoral practice, theologies, and communities.

Further Research

This research is based on interviews with a small number of people from the much larger group of women with dis/abilities; the choice to study a few select individuals omits others and their views. Pastoral theological research is needed that takes into more account the great diversity that exists among women with dis/abilities. For example, I focused on women with visible physical dis/abilities, but my research did not include all women in that category, or even all types of visible physical dis/abilities. No one in my study was dependent upon personal assistants, and women who utilize those services likely have a particular view on life that no one in my interviews or reading noted. I interviewed no men with dis/abilities—another group of persons whose input would have nuanced the results.

I did not explore dis/ability issues from a developmental viewpoint. I made no distinction between women who had dis/abilities at birth and those who acquired them later on in life. I also did not distinguish between the experiences of women in their fifties and women in their twenties. There likely are a number of differences in the experience of dis/ability as one progresses through the life span, and these require further research by pastoral theologians and caregivers. For example, aging changes the body and exacerbates physical dis/abilities. The age at which dis/ability enters a woman's life may affect her experience of her body and her relationships. I did not consider the question of whether certain generations have different challenges than others. For example, do the changes brought about by the Americans with Disabilities Act (ADA) make life less difficult and isolating for persons who more recently acquired a dis/ability?

Further pastoral theological research is needed into the special issues involving children with dis/abilities. I discussed the psychoanalytic concept of mirroring but did not specifically address the issue of the potential complications for parent-child relationships when a child has a dis/ability. Parents sometimes express guilt that their actions contributed to a child's dis/ability. Does guilt play a role in adequate or failed mirroring? Parents may also experience anxiety in caring for a child with dis/abilities, especially if that child requires special attention. Is this anxiety conveyed to the child? In what ways does that affect her sense of self? The ways communities of faith integrate children with dis/abilities into the life of the congregation is also worthy of exploration.

In this dissertation, I focused on ministries of spiritual care in general. Further research is needed on specialized ministries of care, such as pastoral counseling, to or by women with dis/abilities. In what ways, if at all, are dis/ability issues addressed? What role, if any, does being a part of a devalued group play in pastoral counseling for the client and counselor? What effect does dis/ability in one member of the family have on family problems or family systems? What challenges or advantages do women with dis/abilities face as pastoral counselors?

This work touched on biomedical ethics and theological anthropology. I was unable to find much in the literature on biomedical ethics about dis/ability from a religious perspective or on theological anthropology that considers bodily configuration one possible aspect of what it means to be human. These are topics for further study that could have an impact on pastoral theology and practice.

I had originally intended that actual experiences of care within communities of faith be part of my research. This is still an area of interest to me. I would like to

identify and study communities of faith that intentionally include people with dis/abilities. This exploration would pay special attention to the congregations' ministries of care, addressing the following issues: to whom and by whom is care offered; beliefs about God and humans that support this type of intentional community; the nature of interactions between people with dis/abilities and nondisabled people; and the integration of people with and without dis/abilities into the work of the community.

Finally, I began my investigation of the stare with a relatively clear understanding of what it is and how it is experienced. My view was similar to the one usually presented in dis/ability studies literature. Particularly interesting is the idea of the stare as curiosity. Are the women who suggest curiosity as a primary motivation for staring accurate in their assessment? Is the devaluing stare less prominent than suggested by the dis/ability studies literature? Can a curiosity that is not contaminated by negative valuation exist? Is this a generational phenomenon, that is, are younger people with dis/abilities whose lives have been influenced by the Americans with Disabilities Act more likely to name curiosity as a reason for staring than persons for whom ADA advantages came later in life? To determine the extent of curiosity as a motive for staring and curiosity's relationship to popular cultural values, further research would need to include a study of persons who stare and their reasons, assumptions, thoughts, and feelings about this activity and the objects of the stare.

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